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The Experience of Relationships for Young People on the Autism Spectrum

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This thesis is submitted in partial fulfilment of the requirements
for the degree of Doctorate in Clinical Psychology

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Contents

List of tables and figures	8
List of abbreviations	9
List of appendices	10
Acknowledgements	11
Declaration	12
Summary	13
Chapter 1: Victimisation experiences of children and young people who are on the autism spectrum: A systematic review of qualitative literature	14
1.0 Abstract	15
1.1 Introduction	16
1.1.1 Victimisation in context	16
1.1.2 Impact of victimisation on children who are on the autism spectrum	16
1.1.3 Methodological issues	17
1.1.4 Rationale for current review	17
1.1.5 Aims	18
1.2 Method	18
1.2.1 Database search	18
1.2.2 Selection criteria	19
1.2.3 Classification of studies	20
1.2.4 Quality framework	22
1.2.4.1 Results of quality appraisal	22
1.2.5 Analysis	23
1.2.6 Characteristics of studies	23
1.3 Results	30
1.3.1 Aim 1: How do children and young people on the autism spectrum experience victimisation?	31

1.3.1.1 Impact on wellbeing	31
1.3.1.1.1 Negative effects on mental health	31
1.3.1.1.2 Loss	32
1.3.1.1.3 Lack of engagement	33
1.3.1.2 Self as at fault	33
1.3.1.2.1 “That’s just not the way I function”	34
1.3.1.2.2 “Maybe there’s something wrong with me?”	35
1.3.1.2.3 Face-value interpretation	36
1.3.2 Aim 2: How do children and young people on the autism spectrum cope with experiences of victimisation?	37
1.3.2.1 Taking matters into their own hands	37
1.3.2.1.1 Ignore and avoid	37
1.3.2.1.2 Minimisation	38
1.3.2.1.3 Assertion and adaptation	38
1.3.2.1.4 Barriers to taking matters into their own hands	40
1.3.2.2 Seeking support from others	40
1.3.2.2.1 The responsibility of authority figures	40
1.3.2.2.2 The role of the family	43
1.3.2.2.3 Peers as buffers	43
1.3.2.2.4 Barriers to seeking support from others	44
1.3.3 Critique of studies	44
1.3.3.1 Aims	45
1.3.3.2 Context	45
1.3.3.3 Sample	46
1.3.3.4 Recruitment	47
1.3.3.5 Ethical considerations	48
1.3.3.6 Methodology	48
1.3.3.7 Method of analysis	49

1.4 Discussion	49
1.4.1 Limitations	52
1.4.2 Clinical implications	53
1.4.3 Future research directions	55
1.5 Conclusion	56
1.6 References	58
Chapter 2: “I’m vulnerable; don’t get me wrong, I’m vulnerable”: An exploration of the experiences of young women on the Autism Spectrum entering into a romantic relationship.	66
2.0 Abstract	67
2.1 Introduction	68
2.1.1 Autism in context	68
2.1.2 Autism and gender differences	68
2.1.3 Romantic relationships and autism	69
2.1.4 Qualitative research exploring the experiences of women on the AS	71
2.1.5 Rationale for the present study	72
2.1.6 Aim	72
2.1.7 Choice of language	73
2.2 Method	73
2.2.1 Research design	73
2.2.2 Participants	74
2.2.3 Procedure	75
2.2.3.1 Ethical procedures	75
2.2.3.2 Materials	75
2.2.3.3 Recruitment	76
2.2.3.4 Interview procedure	76
2.2.4 Analysis	77
2.2.4.1 Validity of analysis	77

2.2.4.2 Researcher position	78
2.3 Results	78
2.3.1 Navigating ambiguity	79
2.3.1.1 “Like what is it?”	79
2.3.1.2 “I was confused more than anything”	82
2.3.1.3 “I’m not me”	84
2.3.2 Identifying vulnerability	86
2.3.2.1 “I hated it but I did it anyway”	86
2.3.2.2 “I wanted to be kind of normal”	89
2.3.3 Constructing the future self	90
2.3.3.1 “Just a bit more always worried about it”	91
2.3.3.2 “If I’m not ready, I’m not ready”	92
2.3.3.3 “Acceptance is all I mainly want”	94
2.4 Discussion	96
2.4.1 Navigating ambiguity	96
2.4.2 Identifying vulnerability	98
2.4.3 Constructing the future self	99
2.4.4 Limitations	101
2.4.5 Clinical Implications	101
2.4.6 Recommendations for future research	103
2.5 Conclusion	104
2.6 References	105
Chapter 3: Reflections of working with young people on the autism spectrum: navigating ambiguity, vulnerability and the future self.	113
3.1 Introduction	114
3.2 Navigating ambiguity	114
3.2.1 Engagement	114
3.2.2 Diversity or disorder?	117

3.2.3 A girl in a boys' world?	119
3.3 Identifying vulnerability	121
3.3.1 The researcher 'spectrum'	121
3.3.2 Facilitating empowerment	124
3.4 Constructing the future self	126
3.5 References	128

List of Tables

Table 1.1	Search terms	19
Table 1.2	Inclusion and exclusion criteria	20
Table 1.3	Characteristics of reviewed studies	24
Table 1.4	Aims and respective themes	30
Table 2.1	Participant inclusion and exclusion criteria	74
Table 2.2	Participant characteristics	75
Table 2.3	Superordinate and subordinate themes	79

List of Figures

Figure 1.1	PRISMA flow diagram of the study selection procedure (Moher et al., 2009)	21
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List of Abbreviations

ADOS-2	Autism Diagnostic Observation Schedule- Second Edition
APA	American Psychiatric Association
AS	Autism Spectrum
ASD	Autism Spectrum Disorder
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DCP	Division of Clinical Psychology
DFE	Department for Education
DSM-V	Diagnostic and Statistical Manual of mental disorders-fifth edition
ERIC	Education Resources Information Centre
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
NT	Neuro-typical
PDD-NOS	Pervasive Developmental Disorder-Not otherwise specified
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SEN	Special Educational Needs
SRE	Sex and Relationship Education
UK	United Kingdom
USA	United States of America

List of Appendices

A	Author instructions for submission to: <i>Research in Autism Spectrum Disorders</i>	131
B	Ethical approval received from Coventry University Ethics Committee - Literature Review	132
C	Author instructions for submission to <i>Autism & Developmental Language Impairments</i> .	133
D	Quality assessment framework and study scores	135
E	Ethical approval received from Coventry University Ethics Committee- Empirical paper	138
F	Gatekeeper letter and consent	139
G	Participant information sheet	140
H	Participant consent form	141
I	Interview schedule	142
J	Demographic information sheet	144
K	Debriefing form	146
L	Stages of data analysis (Smith, Flowers & Larkin, 2009)	148
M	Excerpt from data analysis	149
N	Photo depicting the process of organising and clustering of emergent themes across participants	150

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Declaration

This thesis has not been submitted for a degree or award at any other university or institution. This research was conducted under the academic supervision of Dr Tom Patterson (Clinical Psychologist, Coventry University) and Dr Jacky Knibbs (Clinical Psychologist, Coventry University). Both supervisors supported me with the development of the research idea and offered feedback and guidance on draft copies throughout the process. A peer from my cohort who was familiar with Interpretative Phenomenological Analysis (IPA) was also involved in coding a single transcript from my empirical study and appraised the quality of six papers from the literature review to enhance validity. Apart from the collaborations stated, this thesis is my own work. The literature review has been prepared for submission to *Research in Autism Spectrum Disorders* and the empirical paper has been prepared for submission to *Autism & Developmental Language Impairments*.

Summary

This thesis is an exploration of the experiences of young people on the autism spectrum as they navigate their social world. There is a dearth of qualitative literature which gives voice to the unique challenges faced by this population within society. The experiences of both victimisation and romantic relationships are explored; phenomena which are well recognised as impacting on wellbeing and mental health. It is hoped that this thesis will contribute to understanding how young people make sense of and manage these experiences to inform future clinical support.

Chapter one is a critical systematic review of the qualitative literature exploring how children and young people on the autism spectrum experience and cope with victimisation. A database search yielded ten studies which met the specified criteria for inclusion. Young people's experiences fell broadly into two themes: impact on wellbeing and self as at fault with methods of coping sought from both internal and external sources. The findings had important clinical and research implications and called for further exploration of the potential impact that the phenomenon may have on this vulnerable group.

Chapter two is a qualitative empirical study which explored the lived experience of romantic relationships for young women on the autism spectrum. Interpretative Phenomenological Analysis (IPA) was employed to analyse the data of five participants from which three superordinate themes emerged: 'Navigating Ambiguity', 'Identifying Vulnerability' and 'Constructing the Future Self'. The findings served to broaden our understanding of the needs of this group to guide future clinical support. Directions for further research and limitations are discussed.

Chapter three is a reflective account of the researcher's experience of conducting qualitative research and working clinically with young people on the autism spectrum. Parallels are drawn between the experiences reported by participants and those experienced by the researcher as a Trainee Clinical Psychologist. The impact of these experiences is discussed in terms of construction of the future self.

Overall word count: 19,629

Chapter 1: Literature Review

Victimisation experiences of children and young people on the autism spectrum: A systematic review of qualitative literature.

Overall chapter word count (excluding tables, figures and references):7998

Written in preparation of submission to *Research in Autism Spectrum Disorders* (see Appendix A for author guidelines)

1.0 Abstract

Background: Victimisation is a widely recognised public health issue due to its severe and pervasive negative impact on wellbeing (Gini & Pozzoli, 2009).

Individuals on the autism spectrum (AS) may be particularly vulnerable due to differences in social skills, difficulty with communication and behavioural

challenges. **Aims:** The primary focus of the systematic review was to critically evaluate the findings of qualitative literature which explored the experiences of victimisation for children and young people on the AS. Specifically, the review aimed to understand what existing qualitative research evidence can tell us about

how young people experience and cope with victimisation. **Method:** Ten articles met the inclusion criteria from a systematic literature search of the databases

PsychINFO, CINAHL, MEDLINE and ERIC. **Results:** The findings revealed that young peoples' experiences fell into two main themes: impact on wellbeing and self as at fault, with methods of coping sought from both internal and external sources.

The phenomenon was, however, complex and idiosyncratic with a range of factors found to mediate young peoples' responses including traits related to autism, gender and perceived efficacy of support. **Conclusion:** The findings have important clinical

implications and suggest the development of preventative interventions whilst fostering autonomy for young people to address their unique needs. A dearth of qualitative literature on the experiences of victimisation for young people on the autism spectrum calls for further exploration of the potential impact that the phenomenon may have on this vulnerable group.

Keywords: *Victimisation, autism spectrum, young people, qualitative, systematic review.*

1.1 Introduction

1.1.1Victimisation in context

Victimisation is a widely recognised public health issue due to its severe and pervasive negative impact on wellbeing (Gini & Pozzoli, 2009). Suicidal ideation and depression are amongst the psychological sequelae and these may persevere in to adulthood for the victimised individual (Sweeting & West, 1998). Due to cultural dimensions and difficulties in drawing distinctions between elements, a consensus definition of victimisation is lacking. Humphrey and Hebron (2014) however, refer to it having the following ‘essential ingredients’: an imbalance of power, an intention to cause harm, repeated over time, taking place in a social setting and being unprovoked.

1.1.2 Impact of victimisation on children on the autism spectrum

Research suggests that children and young people who have a disability are at significant risk of experiencing victimisation (Twyman et al., 2010; O’Connell, Pepler & Craig, 1999). Individuals who are on the autism spectrum (AS) may be particularly vulnerable due to differences in social skills (Kloosterman, Kelley, Craig, Parker, & Javier, 2013), difficulty with communication (Nabuzoka, 2003) and behavioural challenges (APA, 2013). Of note, children and young people who are on the AS have been considered to be four times more likely to experience bullying or victimisation than peers without a disability (Sterzing, Shattuck, Narendorf, Wagner & Cooper, 2012).

1.1.3 Methodological issues

Existing literature has predominantly employed quantitative methodologies to explore the prevalence, nature and characteristics of victimisation experiences of children and young people on the AS (Zablotsky, Bradshaw, Anderson & Law, 2013; Kloosterman et al., 2013). For example, a recent review of the literature highlighted the dominance of questionnaire-based surveys to explore the phenomenon (Schroeder, Cappadocia, Bebkö, Pepler & Weiss, 2014).

The use of qualitative methodologies to understand the nature and characteristics of victimisation from the victim's perspective, although still limited, has recently been increasing (Van Roekel, Scholte & Didden, 2009). There has been considerable focus on reports from parents about their child's experiences of victimisation (Bejorot & Mortberg, 2009; Carter, 2009). However, qualitative studies which capture the views and the first-hand experience of the child victims are particularly important in giving voice to the young person's perspective and broadening our understanding of the phenomenon (Bitsika & Sharpley, 2014). Schroeder et al's (2014) systematic review highlighted the benefits that qualitative studies can make to "shedding light" on this pervasive issue through providing experts by experience with a voice.

1.1.4 Rationale

Despite the limited existing qualitative literature, such research offers an in-depth understanding of the complex issue of victimisation for children and young people who are on the AS (Bolte, 2014). There is therefore a need for the findings of qualitative research in the field, which focuses on the direct experiences of those

who have been affected by this phenomenon, to be critically evaluated and for the findings across such studies to be synthesised in order to inform clinical practice and future research directions. As highlighted in Fisher and Taylor's (2015) recent study:

"We must now move beyond what we think students are experiencing to actually asking them what is happening and how it impacts them." (Fisher & Taylor, 2015, pp. 16).

1.1.5 Aims

The aim of the current review is to critically evaluate findings from the existing qualitative empirical literature that have investigated the victimisation experiences of children and young people who are on the AS, from their own perspectives. Within this, the following questions will be explored:

- How do children and young people who are on the AS *experience* victimisation?
- How do children and young people who are on the AS *cope* with experiences of victimisation?

1.2 Method

1.2.1 Database search

A systematic literature search was conducted between August 2017 and March 2018. Ethical approval was granted for this review from Coventry University Ethics Committee (Appendix B). Databases covering the fields of psychology, education, medicine and nursing were deemed the most relevant for the nature of the study and

included: PsychINFO, Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE and Education Resources Information Centre (ERIC).

Automatic alerts were established for all databases. The key terms used to capture relevant studies are presented in Table 1.1 and included the main concepts of young person, autism, victimisation and qualitative. Synonyms for each concept were then defined and a truncation (*) of specific concepts was used to broaden the search.

Boolean logic was utilised to combine groups of terms.

Table 1.1 Search terms

Main concept	Synonym	Location
Young person	Young people OR Young adult* OR adolesc* OR child* OR teenage* OR student OR pupil	Keyword Abstract
Autism	Autis* OR Asperger* OR Pervasive Developmental Disorder OR ASD OR ASC OR PDD	Keyword Abstract
Victimisation	Victimi* OR bully* OR harass*	Keyword Abstract
Qualitative	Qualitative OR experience* OR view* OR perspective	Keyword Abstract Full text

,

1.2.2 Selection criteria

All articles retrieved from the systematic search process were assessed for eligibility based on specific inclusion and exclusion criteria outlined in Table 1.2. Following this, an additional manual search was conducted which involved consulting the reference list of each eligible article to check for additional relevant studies. Identified studies were then reviewed against the same inclusion and exclusion criteria.

Table 1.2 Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Method	Studies where at least one of the primary aims was to explore the experiences of victimisation for children or young people who are on the AS utilising a qualitative methodology. Studies where the primary aim was not to explore victimisation experiences, but where bullying or victimisation emerged as a significant theme or finding, were included.	Quantitative studies with no qualitative methodology.
Participants	Children or young people on the AS OR children and young people and their parents, carers, teachers and siblings.	Parents, carers, teachers and siblings only.
Language	Studies written in English.	Studies written in a language other than English with no English translation.
Age	4-25 (child or young person) OR adult retrospective reflection on childhood experiences.	Participants aged <5->25 or focussing on victimisation experiences beyond this childhood age limit.
Diagnosis	Studies that explored neurodevelopmental conditions of which autism was included and was distinctly identifiable.	Studies that explored neurodevelopmental conditions of which autism was not one. Studies that were not peer reviewed.
Publication	Papers that had been published in peer reviewed academic journals or unpublished academic theses.	Studies which had utilised qualitative methodologies but with no analysis

1.2.3 Classification of studies

The systematic search followed the process recommended by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009) guidance. The process of selection is presented in Figure 1.1 and led to the identification of ten studies which met criteria for inclusion.

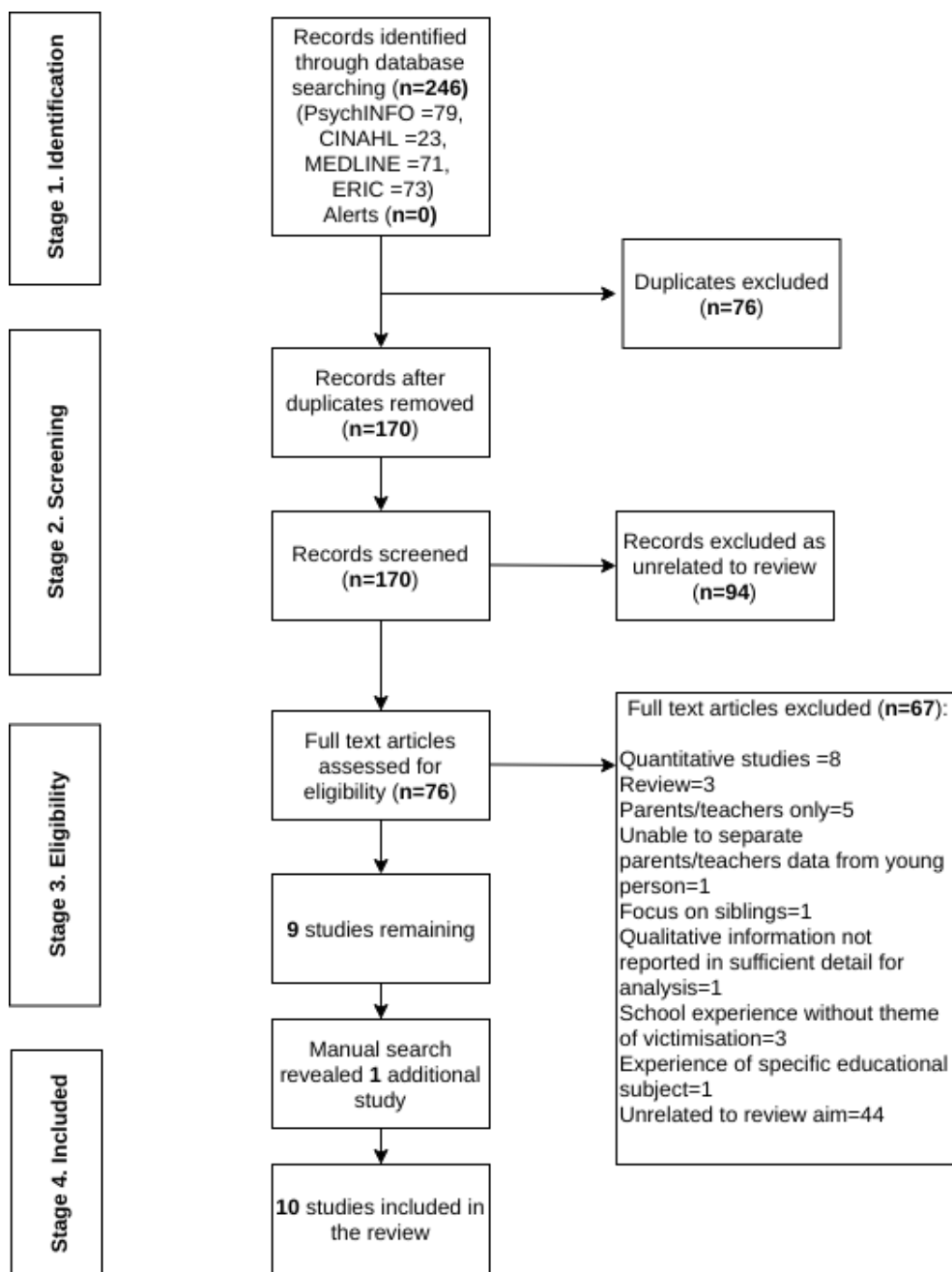


Figure 1.1 PRISMA flow diagram of the study selection procedure (Moher et al., 2009)

1.2.4. Quality framework

Upon completion of the systematic search, the final ten papers were appraised for quality using a quality assessment checklist developed by Caldwell, Henshaw and Taylor (2005). This assessment framework, which can be applied to either qualitative or quantitative studies, was considered appropriate for the present review. Despite debate existing regarding the utility of quality assessments to appraise qualitative research, due, in part, to many of the existing frameworks being written within the quantitative paradigm (Benton & Cormack, 2000; Polgar & Thomas, 2000; Caldwell et al., 2005), the present review utilised Caldwell et al.'s (2005) more flexible framework to assist in the consideration and identification of relative strengths and weaknesses of each study.

1.2.4.1 Results of quality appraisal

All ten studies were appraised against 18 quality criteria (Appendix D) and were assigned a score of '2' points where a criterion had been fully met, '1' point if this had been partially met and '0' if there was no evidence of the criterion being met. Studies were scored from a maximum of 36 points with higher scores indicating a greater number of quality criteria being met; the total scores ranged between 30-35 (mean=32.8). To address the reliability of ratings, six studies were randomly assigned and subjected to independent appraisal by a second reviewer. Statistical analysis of the data, using a kappa coefficient, was performed to determine inter-rater reliability of scores. Whilst discrepancies were found to exist on certain criteria, the overall quality score difference was minimal. All coefficients were above $k=0.75$ indicating substantial agreement with the overall coefficient score calculated as $k=0.82$ suggesting a high level of agreement (McHugh, 2012).

1.2.5. Analysis

Comparison of the data involved identifying reoccurring themes across papers whilst exploring convergence and divergence. This process was undertaken due to substantial methodological heterogeneity between studies. To enable the voices of the young people to be heard, direct quotations from studies have been documented within the results.

1.2.6 Characteristics of studies

The general characteristics of each study are detailed in Table 1. 3 alongside the total quality score and kappa coefficient for the six randomly assigned studies.

Table 1.3 Summary of characteristics of included studies

Author, year, country of origin	Sample size and strategy	Aims and areas covered	Data collection (method, location, timing, researcher position/information) and data analysis (credibility checks)	Participant details: Age, gender, ethnicity, diagnosis, type of school.	Summary of key findings	Quality rating (QR) and kappa coefficient
1. Altomore, McCrimmon, Cappodocia, Weiss, Beran and Smith-Demers. 2017 Canada	N=38 Participants were recruited through community agencies, school divisions, and health offices that provide services to individuals with ASD. In addition, participants from previous research with the corresponding author were invited to participate in the current study.	The study sought to identify specific coping strategies used by students with ASD, who did not have an intellectual disability when confronted with bullying situations. To be used as a precursor to potential future research on the effectiveness of certain strategies.	Tools used for inclusion and exclusion purposes: ADOS-2. Weschler Abbreviated Scale of Intelligence – Second Edition (WASI-II) Semi-structured interviews. Thematic Analysis (Braun & Clarke, 2006)	Thirty-one participants (82%) identified as male Age range: 8-13 years (M = 11.26, SD = 1.58) Predominantly enrolled in a regular classroom (n = 20), some enrolled in a specialised educational environment (n = 10) or a regular classroom with some small group instruction (n = 6). One participant was in a specialized setting with some regular classroom instruction, and one was home-schooled. All had received a diagnosis of ASD.	Thematic analysis yielded three themes: approach coping, avoidance coping, and complexities of bullying. This study provides insight into the coping strategies implemented by students on the AS and possible avenues for school-based intervention.	QR=31 K= 0.79
2. Carrington, Campbell, Saggars, Ashburner,	N=10 Students (Parents=9)	The aim of this study was to gather information about the experiences of children with ASD and their parents about	Semi-structured interviews.	9 Male 1 Female	Data was discussed in the following three categories: understanding and experiences of bullying, recommendations to schools and	QR=30

Vicig, Dillon-Wallace and Hwang. 2017 Australia	Participants in the study were invited to take part through 3 ways: Invitations were posted on the Autism Queensland Facebook™ page, distributed to students (11–16 age range) at Autism Queensland to take home, and distributed to teachers and families of new clients seen by Autism Queensland's outreach services.	bullying and to investigate their recommendations to government and schools in relation to bullying.	Conducted within families' homes. Method of analysis not reported (only software) Ethnicity not reported.	(8 mothers and 1 Father) Age range: 11.5-16.3 students attended mainstream, 1 student was home schooled (6 attended public schools, 2 attended catholic, 1 attended private independent school) All children had a diagnosis of ASD.	recommendations to government.	
3. Cook, Ogden and Winstone 2017 UK	N=11 Purposive sampling Participants were recruited from mainstream and special schools in Southeast England by e-mailing schools, advertising in the National Autistic Society's newsletter and making contact with individuals who had shown willingness to take part through word-of-mouth.	The study explored experiences of learning, friendships and bullying in girls with autism attending both specialist and mainstream schools and those of their parents.	Semi-structured interviews. Conducted within participants' school setting. Thematic analysis (Braun and Clarke 2006) was used to analyse the data.	Female Age range: 11-17 10 White British 1 Mixed Race ASD (3), Autism (3), Asperger's (5) Attended both mainstream and SEN schools.	Three main themes: 1. Motivation to have friends: girls wanted to have friendships and to fit in with other girls, but their notion of having friendships did not always work out successfully in practice. 2. Challenges faced by girls with autism: problems faced by the girls, ranging from communication and friendship group difficulties to social isolation, bullying and absenteeism.	QR=34 K= 0.84

					3. Masking their autism: both a solution and a problem: Many reported how well their daughters coped or how they adjusted their behaviour in order to fit in. As such, this 'masking' behaviour offered a solution to some of their social difficulties. It could also pose a problem, if it led to a late or misdiagnosis.	
4. Cook, Ogden and Winston. 2016 UK	N=11 Purposive sampling Participants were recruited from schools in south-east England.	To explore the experiences of young men with autism with a focus on learning, social relationships and bullying.	Semi-structured interviews. Conducted within participants' school setting. Thematic analysis (Braun and Clarke 2006) was used to analyse the data.	Male Age range: 11-17 White British (8), White Other (1), White (1), Asian (1). All participants had been diagnosed with Autism Spectrum Disorder (ASD) Mainstream and special schools.	Four main themes: 1. Experiences of friendships and bullying 2. Risk factors internal and external 3. Protective factors 4. Outcomes	QR=34
5. Fisher & Taylor. 2015	N=30 As part of a larger study examining the transition	Research questions were: (1) When asked about being teased or bullied, what types of experiences do adolescents with ASD describe? (2) Are adolescents with ASD	Interviews with ADOS-2 Section 6: Social Difficulties and Annoyance Conventional content analysis approach	26 Male 4 Female	Three main themes were identified: 1. Types of victimisation 2. Reasons for bullying 3. Reactions to victimisation	QR=32

USA	from high school in the USA. Participants were recruited through a number of venues, including local clinics and other autism-related research studies, as well as local support groups, service providers, and autism organizations	able to provide reasons as to why they are targeted? (3) How did students with ASD react to instances of bullying?	(Hsieh & Shannon, 2005) Qualitative content analysis was used to establish themes that emerged from responses to the Social Difficulties and Annoyance Section of the ADOS Module 4.	Age range: 17 to 19 years (M = 18.19, SD = 0.49). White, non-Hispanic (27) African American (3) Regular public school (18), regular private school (2), services only children with disabilities (4), Magnet school (2), home school (4)		
6. Humphrey & Lewis. 2008 UK	N=20 Four chosen mainstream secondary schools in the north-west of England.	1. To explore the views of pupils with AS about mainstream education 2. to document the everyday experiences of such pupils in mainstream schools 3 to identify practices in mainstream schools that facilitate or constrain the learning and participation of students with AS 4 to use objectives 1, 2 and 3 to provide a framework for the development of effective inclusive practices in this area.	Semi-structured interviews, pupil diaries, pupil drawings. IPA	Age range: 11–17 years. All attended mainstream secondary schools. All had a diagnosis of AS. Ethnicity not reported.	The central theme was how participants constructed their understanding of what their AS meant to them; this was often characterised by negative perceptions of differences. Links between this understanding and reported difficulties with peers, teachers and the desire to fit it.	QR=32 K= 0.74
7. Humphrey & Symes	N=36	Specific objectives were to (1) identify the role social support plays in determining the pupils'	Semi-structured interviews	Male (32) and female (4). Age range: 11–16 years	Pupil's response to bullying (seeking support: teachers, peers, parents/family) versus going it alone. Mediated by relationships	QR=33 K= 0.75

2010 UK	Recruited from 12 secondary schools north west England.	response to bullying and (2) identify barriers to the development and utilisation of social support where bullying occurs.	Thematic analysis (Braun & Clarke, 2006)	All had a diagnosis of ASD and were on the SEN register.	with potential advocates/sources of support: teachers, peer relationships and related to barriers to the utilisation of social support: traits associated with ASD, lack of trust, desire for solitude).	
8. Penney 2013 Canada	N=5 The individuals selected for this study were sought through advertisement. This was done in 2 ways: A letter introducing the study was sent both to the ASD consultants in the provincial Department of Education and to the Autism Society of Newfoundland and Labrador.	This qualitative study investigated the experiences of adolescents and young adults diagnosed with an autism spectrum disorder (ASD) and co-occurring depression and/or anxiety disorders.	Purposeful sampling The study used open ended, online (3) and face-to-face (2) Interviews. Interpretative Phenomenological Analysis (IPA) Researcher position not reported	Age range: 16-21 4 males, 1 female All attended mainstream school 4 received a diagnosis of AS. 1 received a diagnosis of PPD-NOS.	Four main themes: Behaviour intervention, early identification of learning and sensory issues and use of appropriate accommodations, Prevention of victimization, prevention and early intervention with mental health.	QR=35
9. Robertson 2013 USA	N=13 The researcher sent a recruitment email message to two listservs used by families of autistic youth. These listservs' members reside in the Central Pennsylvania and the	The research inquiry aimed to learn more about how bullying affects the perspectives and experiences of autistic youth. Additionally, the researcher wanted to learn about how autistic youth address bullying and report it to parents, teachers, and other	Mixed methods design: Semi-structured interviews with young people, surveys completed by both young people and their parents. Conducted within participants' schools or	Male (12) female (1) Age range: 13-18 The participants had a median age of 16 and a mean age of 15.85.	Six main themes emerged: T1. Bullying Shapes Autistic Youths' Experiences, Emotions, and Perceptions T2. Face-to-Face Bullying Exerts Greater Physical Control T3. Ignoring/Avoiding Cyber- and Face-to-Face Bullying: A Defensive Strategy T4. Parental Monitoring Deters Cyberbullying	QR=35 K= 1

	Washington D.C. metropolitan areas. Purposive sampling.	authorities. This pursuit reflected a goal to contribute to the research base on bullying and fill in existing gaps.	home of colleague of researcher. 30-45 minutes interviews	Data analysis based on La Pelle (2004). White Caucasian (84.6%), Black/African American (7.7%), American Indian or Alaskan Native (7.7%).	T5. Social-Cultural Barriers Can Hinder Reporting Bullying T6. Assistance from Allies to Address Cyber- and Face-to-Face Bullying	
10. Saggers, Campbell, Dillon-Wallace, Ashburner, Hwang, Carrington and Tones. 2017 Australia	N=10 Advertisements were posted on both the Autism Queensland Facebook page and through the email communications of Asperger Services Australia. In addition, invitations were distributed to students (11–16 age range) at Autism Queensland to take home, as well as to teachers and families of new clients seen by Autism Queensland's outreach services.	Specific aims of the current study were to investigate: • students with ASD's experiences of bullying, and • the impact of these experiences on their personal wellbeing and schooling.	Semi structured interviews. Three phone interviews, one face-face held at the university, six face-face interviews held at participants' homes. 20-65 minutes in length. Thematic Analysis (Braun & Clarke, 2006). Data triangulation	Male (9) and female (1) Age range: 11 years 5 months to 16 years 3 months. Six of the students attended public schools, two attended Catholic schools, one student attended an independent school, and another was home schooled. Asperger's Syndrome (7) ASD (3)	Three main themes were identified from the transcribed interview data: 1. understanding of bullying 2. experiences of bullying behaviour 3. responses to bullying. Four subthemes emerged from the main themes: 1. Type of bullying 2. situational factors 3. responding to and reporting bullying 4. Impact of bullying behaviour on victim	QR=32 K= 0.83

1.3 Results

The findings from the present review are summarised in Table 1.3. The paper discusses the findings thematically in relation to the aims, followed by a critique of the studies. The first aim was to determine how children and young people on the AS experience victimisation and the second aim was to explore how young people cope with these experiences. The majority of studies addressed both aims despite not all focussing on bullying or victimisation experiences specifically. Where possible, the distinct experiences of males and females are highlighted.

Table 1.4 Aims and respective themes

Aims	Themes and subthemes
1. How do children and young people on the AS experience victimisation?	<ul style="list-style-type: none">• Impact on wellbeing<ul style="list-style-type: none">○ Negative effects on mental health○ Loss○ Lack of engagement• Self as at fault<ul style="list-style-type: none">○ ‘That’s just not how I function’○ ‘Maybe there’s something wrong with me?’○ Face-value interpretation
2. How do children and young people on the AS cope with experiences of victimisation?	<ul style="list-style-type: none">• Taking matters into their own hands<ul style="list-style-type: none">○ Ignore and avoid○ Minimisation○ Assertion and adaptation○ Barriers to taking matters into their own hands• Seeking support from others<ul style="list-style-type: none">○ The responsibility of authority figures○ The role of the family○ Peers as buffers○ Barriers to seeking support from others

1.3.1. Aim 1: How do children and young people on the AS experience victimisation?

1.3.1.1 Impact on wellbeing

1.3.1.1.1 Negative effects on mental health

An intense experience of fear and anxiety was experienced by the victimised young person including reports of panic attacks associated with their personal school experiences (Penney, 2013; Saggars et al, 2017; Humphrey & Symes, 2010).

Continuity of experiences was encountered between primary and secondary school with some young people fearing further repetition in future settings. For example, one young person described treatment by his peers as “hard in primary, it’s worse in high school...I’m afraid to go to college if that happens” (Saggars et al, 2017, p. 16) suggesting that continued victimisation was inevitable. Additionally, victimisation had led some young people to experience anxiety when in contact with any peers, reporting that when classmates came near they became “anxious and stressed” with one young person feeling “stressed all the time” (Humphrey & Symes, 2010; p87).

Young people reflected on the longer-term consequences of being victimised including the experience of the emotional impact “permeat(ing)” defences and reducing self-esteem (Robertson, 2013, p.127). A gradual “breaking down” of self-esteem had led some to feel that they were not “worth anything” (Robertson, 2013; p127). A number of papers reported that young participants perceived there to be a direct impact of victimisation on their mental health, including experiencing suicidal ideation and suicide attempts, depression, experiencing nightmares and reliving traumatic events and engaging in self-harm behaviours with several young people requiring intervention from mental health services (Cook et al, 2016; Penney, 2013;

Robertson, 2013). Attempts to end their own lives or to self-harm were recognised as an expression of not coping by young people and manifested in a variety of ways including cutting of wrists (Penney, 2013) and swallowing batteries (Cook et al, 2016). In one study, victimisation experiences had involved being implicitly told “(He) should die” by the perpetrators, while another participant had drawn a picture depicting his own death (Humphrey & Lewis, 2008). Others reported how social isolation had been a consequence of victimisation which had subsequently impacted on their mental health; feelings of depression were reported by young people between and within several studies (Penney, 2013; Robertson, 2013).

The perceived direct impact of victimisation experiences on mental health was of particular significance in Penney’s (2013) study. One young person reported feeling that, if he had been protected from bullying, he may not have had the serious mental health issues he experienced, including a suicide attempt. It is important to highlight that this study included only young people who self-identified as having co-occurring anxiety or depression, while a number of participants in the study did not attribute their mental health difficulties directly to victimisation experiences.

However, a detrimental impact on mental health was a theme that emerged across a number of papers.

1.3.1.1.2 Loss

A sense of loss was evident in relation to childhood innocence or identity and how the young person felt they “should” be or have been; this was poignantly described by one young person who described themselves prior to experiencing bullying as “a go-lucky kid that just wanted to have friends and fun and just have a good life” in

contrast to his perceived reality which had “never been that” (Saggers et al, 2017, p. 16). For others, a loss of or disruption to memory and an inability to recall events was reported. Some described how they had “blocked out the memories” highlighting the traumatic nature of the experiences that they had been exposed to (Fisher & Taylor, 2015; p. 9; Cook et al, 2017; p259).

1.3.1.1.3 Lack of Engagement

Low mood was reported to impact upon school attendance, interest in activities and an increase in social isolation (Penney, 2013; Robertson, 2013; Saggers et al, 2017). Young people reflected on the negative impact on specialist interests as a particularly painful experience; often such interests were described as identity shaping and purpose providing. Some reported attempting to quit their pursuits (Robertson, 2013) or losing interest in once pleasurable activities (Penney, 2013) as a result of victimisation. Furthermore, school absenteeism was highlighted as both a coping strategy and a consequence of the emotional impact of being victimised (Cook et al, 2017; Saggers et al, 2017; Penney, 2013). For some, this resulted in leaving school permanently; one young person recalled how he realised “I can’t go there (school) anymore” (Saggers et al, 2017; p. 88) and for others, became a challenge in itself (Cook et al; 2017). Interestingly, all reports of absenteeism in Cook et al’s (2017) study were from girls who attended mainstream schools.

1.3.1.2 Self as at fault

In over half of the studies reviewed, young people engaged in a sense making process which resulted in attributing the cause of victimisation to themselves; specifically, traits associated with autism.

1.3.1.2.1 ‘That’s just not the way I function’

Young people reflected on a perceived divergence between themselves and their peers, with several alluding to being “different”. This was reported in a variety of ways including interests (Cook et al, 2017; Robertson, 2013; Penney, 2013, Humphrey & Lewis, 2008), preference for solitude (Humphrey & Symes, 2010), sensory differences (Cook et al, 2016) and behaviour (Fisher & Taylor, 2015; Penney, 2013). Such divergence was experienced as something innate that could not be altered by several young people. When reflecting on victimisation experiences, one young person reported “I wish I could get along better with other people, but that’s just not the way I function” (Cook et al, 2017. P.6). In one study, young people reported being “naturally shy” and “a bit of a quiet character” as barriers to social integration and therefore increased their vulnerability to bullying (Humphrey & Symes, 2010. P. 88). Others attributed being “obviously different” due to having a disability as the reason for being targeted by bullies with peers' knowledge of their diagnosis of autism perceived to be a direct cause of being “pick(ed) on” (Humphrey & Symes, 2008, p. 34).

In contrast, some young people had difficulty in determining specific personal traits which may have led to victimisation with many reporting not knowing what the differences between themselves and others were. Not being able to determine what these traits may be, appeared to cause some participants further distress and led to generalising, for example, one young person reported “I just don’t do well with kids in high school” (Fisher & Taylor, 2015; Penney, 2013).

1.3.1.2.2 ‘Maybe there’s something wrong with me?’

Experiencing victimisation led some young people to conclude that there is “something wrong with (them)” (Robertson, 2013. P. 116). A desire to be normal was reported by one young person in Humphrey and Lewis’ (2008, p. 31) study with another describing having autism as “It’s like I have a bad brain” indicating a potential to develop a pathologised view of themselves.

Reflecting on personal attributes, participants reported on their own role in experiencing relational difficulties with some blaming themselves for not being “approachable”, not making “attempt(s)” to engage with others or going through “an awkward phase” during adolescence (Fisher & Taylor, 2015, p. 6). In two studies, (Fisher & Taylor, 2015; Humphrey & Symes, 2008) young people described themselves as “easy pickings” and targets for ridicule as they considered themselves to have “over-reacted” to experiences and possessing an eagerness to form meaningful friendships; such social naivety appeared to be exploited by peers. This led some to consider whether they themselves were responsible for the victimisation occurring, with one young person questioning whether this “was kinda my fault?” (Fisher & Taylor, 2015)

It is important to note, however, that the above finding contrasts with findings in a study by Humphrey & Lewis’ (2008) study, where young participants who referred to having a social network, generally reported acceptance and celebration of their differences. It therefore suggests the potential for friendship to perhaps act as a buffer to victimisation for young people on the AS.

1.3.1.2.3 Face-value interpretation

In addition to attempting to make sense of their experiences through attributing the cause of victimisation to personality traits, in three studies, young people highlighted a difficulty in interpreting communication and the intentions of others. In Penney's (2013, p. 87) study, one young person described experiencing "joking" by his peers which included name calling and hiding of his belongings. Young participants reported accepting these actions as "joking" when told this by their peers; however they also perceived an adverse impact on their self-esteem and mental health.

Difficulty in interpreting whether the behaviours of peers were jocular or offensive was further reported by young people in Robertson's (2013) study with one young person describing how those who had been perceived to be friends had "started being mean to (him), beating (him up) and threatening (him)" and another who had been befriended by a peer prior to them stealing their belongings.

Additionally, interpreting information or actions literally posed a challenge for the young people in the Humphrey & Lewis' study (2008). Two young people reflected on experiences that had involved peers appearing to include them and specifically feigning interest as a potential friend. Upon reflection, young people reported how they had not interpreted the actions as bullying in the moment, however, subsequent exposure to ridicule had increased their vigilance for victimisation from their peers. This highlights a particular challenge that young participants were faced with in terms of understanding subtleties and nuances in interpersonal contexts.

1.3.2. Aim 2: How do children and young people who are on the AS cope with experiences of victimisation?

1.3.2.1 Taking matters into their own hands

1.3.2.1.1 Ignore and avoid

A common strategy, identified across many studies, was to ignore or attempt to “not listen” to verbal bullying. This was recognised as being the first attempt at personally managing the situation and was deemed a successful short-term strategy; however, young people reported this not proving effective when sustained for prolonged periods (Altomore et al, 2017; Fisher & Taylor, 2015; Penney, 2013, Robertson, 2013) or if physical bullying occurred (Fisher & Taylor, 2015) . Emphasis was placed on the temporary effectiveness of this strategy in five studies, with young people highlighting that if the bullying behaviour was a “one time thing...and never happens again” then ignoring could be beneficial (Altomore et al, 2017; p. 217), however, when persistent, ignorance could cause perpetrators to “work harder” (Penney, 2013, p. 87). The cognitive processes involved in the use of this strategy varied between studies including ignoring as a method of “wait(ing) for the bullies to go away” or to prevent the bully from achieving a desired effect (Altomore et al, 2017, p. 217; Fisher & Taylor, 2015). In contrast, however, several young people’s reports of the use of avoidance strategies implied a level of acceptance. For example, several studies (Altomore et al, 2017, p. 217; Humphrey & Lewis, 2008, p. 34) found that when predicting how they would react to victimisation, young people reported that they would “do nothing” or “just live with it” and, in response to cyberbullying, highlighted its irrevocable permanence suggesting a degree of learned

helplessness. For others, avoidance strategies reflected uncertainty regarding how to approach the situation due to being “unsure” or not knowing how best to respond.

Young people also reported avoidance as a method of coping which manifested in a variety of ways including walking away, positioning themselves “far away” within the school setting, hiding, moving class and leaving school temporarily or even permanently (Altomore et al, 2017; Robertson, 2013). For some, avoidance of perpetrators had prevented engagement in usual activities, which had a negative impact on wellbeing (Cook et al, 2017).

1.3.2.1.2 Minimisation

An interpretation of young peoples’ responses to their experiences had been described as possible minimising in two studies. Some young people were found to minimise the impact of victimisation through the use of dismissive statements. In Fisher & Taylor’s (2015, p. 8-9) study young people stated, “I know, poor me” and “sad for me, oh well” indicating a need to reduce the severity of the recollection. Other young people stated that incidents had not been “too serious” or “mean” and alluded to victimisation being a common experience within society. Hence, this finding suggests that young people may be attempting to reduce the divergence between themselves and their peers or they may have difficulty interpreting their experiences.

1.3.2.1.3 Assertion and adaptation

Several studies found that some young people reported “standing up to” bullies by: telling them to stop, using threatening language with the aim of intimidation and by

adapting their behaviour to inform perpetrators not to “mess with them” (Altomare et al, 2017; Fisher & Taylor, 2015, p.8). It is important to note, however, that Altomare et al’s (2017) study involved young people reporting on how they, or a fictitious character, would respond to victimisation. The extent, to which this finding is representative of how young people may respond in real life situations, may be limited.

Reflecting on, and adapting, personal behaviour was reported in several studies and involved young people attempting to control their emotions, including “mellow(ing) out” whilst others described an increased vigilance to what was verbalised during interactions with perpetrators (Fisher & Taylor, 2015). In Cook et al’s (2017), female only study, young women reported the utilisation of a strategy which involved consciously changing or 'masking' their personality to conceal their differences (Cook et al, 2017). For some, this was a successful strategy as it prevented social difficulties and isolation, however for others; masking led to emotional outbursts at home and increased absenteeism.

Despite the majority of young people across studies reporting low self-esteem, some drew upon personal resources to cope with and mitigate the effects of bullying. Some reported using self-talk to reframe and minimise the emotional impact of bullying; “If he’s making me feel rubbish I just think “well he’s not exactly a great human being”” (Cook et al, 2016, p. 262; Robertson, 2013) whereas others used humour to protect themselves. The development of a sense of identity and increased self-esteem was also gained through specialist interests, academic achievements and talents. Altomare et al. (2017) reported a degree of resilience in participants' creative

problem-solving suggestions to bullying scenarios; however, it is difficult to determine whether such strategies would be employed by young people in reality.

1.3.2.1.4 Barriers to taking matters into their own hands

Young people described a range of barriers to the effectiveness of personal strategies including fear of being viewed as “kind of stupid” by their peers for ignoring bullying behaviour or of experiencing indirect victimisation by teaching staff which involved being punished for retaliating (Altomare et al, 2017, p. 216; Penney, 2013; Saggars et al, 2017). One young person expressed a belief that their response would not achieve the desired result, suggesting a lack of confidence in their ability to respond in an appropriate and effective way: “I’d get in trouble probably...because usually when I say something back to the person, I say it louder, and then I get in trouble” (Altomare et al., 2017, p. 216).

1.3.2.2 Seeking support from others

1.3.2.2.1 The responsibility of authority figures

The most common coping response to victimisation for young people across studies involved seeking social support from an authority figure; specifically, teachers, however, reporting the behaviour to a head teacher or the police was also suggested. Across the studies reviewed, the extent to which this was perceived as helpful to the situation varied considerably.

In Humphrey and Symes’ (2010) relatively large sample (n=36), young people reported feeling confident in approaching teachers to seek support, highlighting teachers’ ability to effectively manage bullying behaviour which resulted in young

people perceiving their experiences to have been taken seriously. Similarly, a young person in Robertson's (2013, p.118) study described the utilisation of an anti-bullying policy, which "helped out a lot" with prevention of further victimisation. In contrast, findings from other studies indicated that participants experienced the response of teachers as unhelpful or ineffective. Across studies, a number of reasons for this were identified, including: a lack of understanding of the challenges faced by young people on the AS (Humphrey & Symes, 2010; Penney, 2013), not having the power to prevent it (Carrington et al, 2017; Humphrey & Lewis, 2008; Saggars et al, 2017), indirectly contributing to the victimisation (Penney, 2013; Robertson, 2013) or actions not reflecting the severity of the problem (Cook et al, 2017; Fisher & Taylor, 2015). Experiencing indirect victimisation due to people in positions of authority lacking the skills to intervene effectively was poignantly reported by one young person in Robertson's (2013, p. 133) study; "The biggest mark is left by the authority systems that are put in place to prevent this stuff and fail to do anything". Experiencing teachers as "doing nothing" emerged as a finding in five studies where young people had attended mainstream settings (Carrington et al, 2017; Humphrey & Lewis, 2008; Penney, 2013; Robertson, 2013; Saggars et al, 2017).

A call for penalties for perpetrators was expressed by young people including clear school policies to tackle the issue of bullying and harsher consequences (Carrington et al, 2017; Cook et al, 2016). In Carrington et al's (2017, p. 1055) study, one young person stated "I reckon schools should make the bully realise that there are serious consequences for what they have done" suggesting that communication had been lacking regarding the existence of policies within schools to address bullying. A desire for the perpetrator to experience the distress of the victim was evident in

several studies and reflected the impact of victimisation on young peoples' wellbeing, including social isolation; "They should be isolated, you know. Make them feel exactly how the person that has been the victim". In other studies, participants described thoroughly documenting and compiling evidence of their experiences due to feeling dismissed by their school (Fisher & Taylor, 2015; Humphrey & Lewis, 2008; Robertson, 2013); one young person expressed an intention of presenting the written evidence to a member of authority upon completion of school. Conversely, Cook et al's (2016) study found that all young people who attended SEN schools, with the exception of one, reported that despite experiencing victimisation, a zero-tolerance approach and effective methods of response were utilised within those settings.

In four studies, trusting the teacher who the victimisation had been reported to was cited as the most important consideration, however for others, convenience was a major factor when seeking external support (Humphrey & Symes, 2010). A need for staff to approach the young person was expressed in several studies; suggesting that involvement of others could be helpful but would need to be initiated by the teacher (Carrington et al, 2017; Humphrey & Symes, 2010). A fear of being blamed for the actions of others and possessing a strong sense of justice were additional factors found to encourage participants to report bullying (Saggers et al, 2017, p. 16): "I would just tell an adult what they said so I wouldn't get in trouble as well". Importantly, however, reporting bullying behaviour was reported as a vulnerability factor to victimisation in one study (Penney, 2013).

1.3.2.2.2 The role of the family

The role of parents or family members as a method of support, varied across studies. Humphrey and Symes (2010) argued that decisions regarding the involvement of others depended upon the perceived efficacy of response. Others reported not being able to “see the point” in parents being informed of their victimisation experiences as their ability to offer a solution may be limited (Humphrey & Symes, 2010, p.88). For those who reported successful support from siblings, being able to defend the young person in-action or reduce the impact of the victimisation appeared to be important factors. In addition, any family member who dealt with victimisation directly, for instance warning the perpetrators or following up the reports with school, was reported to have a beneficial impact (Humphrey & Symes, 2010; Saggars et al, 2017). In one study, however, reporting victimisation experiences was avoided for fear of causing parents emotional distress; this finding highlighted the complex decision-making process that young people who are on the AS may experience when considering who or how best to involve others (Saggars et al, 2017).

1.3.2.2.3 Peers as buffers

The presence of supportive peers as a buffer to victimisation was a salient finding in four studies (Cook et al, 2016; Humphrey & Lewis, 2008; Humphrey & Symes, 2010; Robertson, 2013). Friends offered social support which enabled validation of experiences following incidents as well as a source of advice; some reported their ability to “stick up” for them or “do something about it” (Humphrey & Lewis, 2008; Humphrey & Symes, 2010, p. 87.). In one study, friendships enabled a young person to cope when perceiving his life as “me against the world” (Robertson, 2013,

p. 136). In addition, support offered from peers was argued to increase resilience and a positive sense of self by Humphrey and Lewis (2008).

1.3.2.2.4 Barriers to seeking support from others

A perception that support seeking might exacerbate victimisation was expressed including a fear of being “made fun of for telling” (Altomore et al, 2017, p. 218). Furthermore, trust was an important emergent theme across the reviewed studies. Distrusting peers and teachers was a common experience reported by young people and was highlighted as both a significant barrier to support and an outcome of experiencing victimisation (Humphrey & Symes, 2010; Saggars et al, 2017). Additionally, difficulty interpreting the intentions of others was a recurring cause of reluctance to seek the support of others, for example, one young person described his concern about peers “switch(ing) back to being a bully” upon disclosure of personal information (Humphrey & Symes, 2010. P. 88).

1.3.3 Critique of studies

All studies scored between 30 and 35 (mean= 33) out of a maximum quality score of 36 indicating that they were of consistently high quality. The findings provided a rich and detailed account of young people's experiences and studies were found to develop inclusive and creative means of data collection to address young people's social communication needs. These included diaries, drawings and online methods in addition to interviews (Humphrey & Lewis, 2008; Penney, 2013). It is important, however, to be aware of the methodological limitations of reviewed articles.

1.3.3.1 Aims

Variation existed across studies regarding individual research aim, with only two studies specifically designed to understand the experience of victimisation for young people on the AS (Fisher & Taylor, 2015; Saggars et al., 2017) and two which aimed to determine the coping strategies employed by young people (Altomare et al., 2017; Humphrey & Symes, 2010). Other aims included; a more general focus on the experiences of the school setting in which bullying was included (Cook, Ogden & Winstone, 2016; Cook, Ogden & Winstone, 2017; Humphrey & Lewis, 2008) and suggestions for prevention (Carrington et al., 2017). Additionally, one of the highest quality rated studies aimed to gain an understanding of all reported factors (Robertson, 2013). This variation suggests that studies did not necessarily explore the same elements of the victimisation experience for young people, with the focus of each individual study being influenced or determined by the study aims.

1.3.3.2 Context

Four of the studies were conducted in the UK (Cook, Ogden & Winstone, 2016; Cook, Ogden & Winstone, 2017; Humphrey & Lewis, 2008; Humphrey & Symes, 2010) with the remaining six in Australia (Carrington et al., 2017; Saggars et al., 2017), Canada (Altomare et al., 2017; Penney, 2013) and the USA (Fisher & Taylor, 2015; Robertson, 2013). Despite all studies reflecting western society, cultural effects may exist on different forms of bullying, how it is experienced, attributed and managed by the victim and wider support systems. Differences in policy, attitudes and values may also make cross-cultural comparison a difficult task. The context of such difference was not addressed in the majority of studies with the exception of

Carrington et al's (2017) and Penney's (2013) study, thus it was not possible to determine the potential influence of this on young people's experiences.

1.3.3.3 Sample

In over half of the papers, sample sizes were small, however, five studies' sample sizes ranged between 20 and 36. In eight out of the ten studies, a significantly higher ratio of male to females participated with one study not reporting the gender demographic (Fisher & Taylor, 2015); consequently there may be a gender bias in the findings, with an underrepresentation of females across most of the studies. This is perhaps not a surprising finding considering the ratio of males to females diagnosed with autism is predicted to be 3:1 (Loomes, Hull & Mandy, 2017).

However, it is thought that this ratio may underestimate the true incidence of autism among females, reflecting findings that autism expresses itself in subtly different ways in girls than in boys (Bargiela, Steward, Mandy, 2016). The greater number of reports of masking behaviour seen in Cook, Ogden and Winstone's (2017) all female study provides one example of potential gender differences in autism.

Additionally, in the three studies which reported on the demographic of ethnicity, white participants were the majority. Interestingly five of the reviewed studies, however, did not provide this information (Altomare et al., 2017; Carrington et al., 2017; Humphrey & Lewis, 2008; Humphrey & Symes, 2010; Saggars et al., 2017). This may indicate that ethnic minorities are underrepresented in qualitative literature exploring the experiences of victimisation in young people on the AS, however, it is not possible to draw firm conclusions as this information has not been made available in most instances.

Furthermore, half of the studies consisted of young person and parent dyads (Carrington et al, 2017; Cook, Ogden & Winstone, 2016; Cook, Ogden & Winstone, 2017; Penney, 2013) with the majority being interviewed simultaneously. Young peoples' ability to openly discuss their experiences may have been compromised due to the presence of a parent within the research design. This may have been a limitation, as participants may have reported what they considered to be acceptable in this context due to social desirability bias thus limiting the extent to which reports were truly representative of experiences.

1.3.3.4 Recruitment

The majority of studies recruited participants through purposive and convenience sampling, however only two studies specifically stated this (Cook, Ogden & Winstone, 2017; Penney, 2013). Most studies recruited participants from schools, social media forums or by advertising on national charity websites with young people's participation reliant upon parental or teacher interest and consent. It is therefore difficult to determine whether young people would have considered their experiences to be victimisation or whether their participation was in part influenced by the recognition of others. Additionally, in two studies, monetary incentives had been employed to aid recruitment (Carrington et al., 2017; Saggers et al., 2017). Debate exists regarding whether financial rewards in research may have a coercive impact and the potential effects of this require further consideration in future qualitative studies (Head, 2008).

1.3.3.5 Ethical considerations

Half of the reviewed studies reported minimal information regarding measures taken to address ethical considerations, with only four stating that ethical approval had been granted and that consent had been sought. Some however provided detailed information regarding attempts to minimise distress (Humphrey & Lewis, 2008; Humphrey & Symes, 2010; Saggars et al., 2017). Due to the sensitive nature of the phenomenon explored and the recognition that young people on the AS are a vulnerable group, consideration of the impact on participants is of particular importance to reduce potential distress and anxiety.

1.3.3.6 Methodology

A description of methods used were generally comprehensive across articles, however, only one of the papers discussed their rationale for adopting specific methodologies or evidenced consideration of alternatives (Robertson, 2013). The method of data analysis varied, with most researchers employing thematic analysis by Braun and Clarke (2006; n=6) and La Pelle (2004; n=1). Two studies, however, employed IPA methodology and one used content analysis. Most studies utilised semi-structured interviews for data collection with some specifying the use of open-ended questions (Altomare et al., 2017; Cook et al., 2016; Cook et al., 2017) One, however, used an unstructured format (Penney, 2013) and two provided no detail about the type of schedule used (Humphrey & Lewis, 2008; Humphrey & Symes, 2010). The ADOS-2 (Lord et al., 2012) was utilised as an inclusionary measure in one study (Altomare et al., 2017) and as the method of qualitative data collection in Fisher & Taylor's (2015) paper.

An important methodological limitation was the lack of a reflexive account of the researchers' influence with only two studies (Robertson, 2013; Penney, 2013) making reference to their position or the use of measures to reduce bias.

1.3.3.7 Method of analysis

All studies provided detailed information regarding choice and method of analysis with the exception of one (Carrington et al., 2017) who only stated what software was used. The majority provided sufficient quotes to evidence their findings; however, one used minimal quotes to reflect the voice of the young person (Fisher & Taylor, 2015) and more prominence was given to parents' perceptions (Penney, 2013). The validity of findings may therefore be questionable in these studies as it is difficult to determine how representative they are of young people's experiences.

1.4 Discussion

The primary focus of the present review was to critically evaluate the findings of qualitative literature which explored the experiences of victimisation for children and young people who are on the AS. The review aimed to specifically understand how young people experience and cope with victimisation.

The experiences of young people fell into two main themes: impact on wellbeing and self as at fault with methods of coping sought from both internal and external sources. The findings of the current review build on previous reviews which have focussed on prevalence and risk factors of victimisation for young people on the AS (Schroeder, Cappadocia, Bebeko, Pepler & Weiss, 2014; Maiano, Normand, Salvas, Moullec & Aime, 2015; Sreckovic, Brunsting & Able, 2014) and extend the findings

of Humphrey and Hebron's (2015) 'State of the field' review which highlighted the paucity of research reflecting the voice of the young person.

The present review demonstrated the complex nature of victimisation experiences for young people on the AS and highlighted their challenges in obtaining both recognition and adequate support. Consistent with previous reviews (Humphrey & Hebron, 2015; Schroeder et al, 2014; Sreckovic, Brunsting & Able, 2014), the findings of the current review indicated a relationship between experiencing victimisation and mental health difficulties including anxiety, depression and suicidal ideation. The experience of loss, however, was present within the literature; an outcome that had not been acknowledged in previous reviews and further demonstrates the complex and multifaceted experience of victimisation. Loss experiences may not be acknowledged or fully understood within society; placing such young people at risk of an experience recognised as disenfranchised grief (Doka, 1999). Many young people across the reviewed studies did not perceive teachers to have responded in a way which matched the severity of the victimisation that they have been exposed to which may have prevented them from expressing their experiences of loss. For others, however, memory loss was reported, a symptom indicative of the likely presence of dissociative amnesia, a condition in which individuals have an inability to retrieve specific unpleasant memories (American Psychiatric Association, 1994). Dissociative amnesia often follows a traumatic event and is usually considered to be a way of managing the conflict or painful effects of such experiences. Other symptoms of trauma have been reported by young people who have experienced bullying in the research literature, further

emphasising the degree of severity of victimisation experiences for young people on the AS and its detrimental impact on wellbeing (Idsoe, Dyregrov & Idsoe, 2012).

Additionally, young people were found to engage in a sense-making process to understand their experiences, with many attributing the cause of maltreatment to themselves. Characterological self-blame is a form of attribution which involves individuals perceiving the cause of negative experiences as uncontrollable, internal and stable (Janoff-Bullman, 1979). It is not possible to determine whether this was a vulnerability factor for young people or a consequence of victimisation and thus warrants further investigation. Research indicates that this trait may pose as a risk factor to persistent peer victimisation for children in the general population (Schacter, White, Chang & Juvonen, 2014).

An important finding, which may indicate gender differences, was young peoples' attempts to adapt themselves in order to 'fit in' with peers to reduce the risk of being targeted by perpetrators. Despite this finding emerging across several papers of mixed gender, the strategy of 'masking' was most prominent in Cook, Oden & Winstone's (2017) paper, the only all-female study included in the review. This has recently been recognised in the literature as a trait often reported by females on the AS which has proved to be both advantageous and disadvantageous (Tierney, Burns & Kilbey, 2016). Masking and imitation may inadvertently prevent young people on the AS from receiving necessary support due to appearing superficially competent. The current review therefore builds on these findings as masking may be employed as a buffer to exploitation. However, this may have relatively short-term benefits, as emotional outbursts at home and absenteeism were reported by many young women.

Such findings point to a need for a greater understanding of the experiences of females who are on the AS.

Furthermore, the findings indicate that young people on the AS engage in a decision-making process to determine whether to seek support based on factors including the perceived effectiveness, availability, accessibility and trustworthiness of others. This suggests that school staff may be best placed to intervene 'in-action' to best meet the needs of young people on the AS. This is underlined by the finding of the current review that authority figures were the most frequently reported source of support.

Finally, it is important to acknowledge the resilience of young people on the AS who had experienced victimisation which was not explored in previous reviews. The findings demonstrated some participants' ability to employ effective strategies which drew upon personal strengths including the use of humour and positive self-talk to reduce distress. In addition, despite not always being effective, many young people were found to attempt to problem solve, which may indicate a wish to address victimisation autonomously. Interestingly, this would be consistent with wider findings from childhood victimisation literature studying the general population (Hinduja & Patchin, 2017).

1.4.1 Limitations

Despite the implementation of purposefully broad inclusion criteria, to capture as many articles as possible, only ten articles were yielded from the search including an unpublished academic thesis. As this had not been obtained from a peer-reviewed journal, the extent to which the findings had been disseminated may have been

limited. Furthermore, despite eight studies recruiting mixed gender samples, and one all-female sample, the majority of participants were male. Findings, however, suggested that unique gender differences may exist, including the potential for females to 'mask' difficulties. Additionally, the potential for some young people on the AS to minimise their experiences may suggest that participants across studies were biased towards those who perceived themselves to have been victimised; the experiences of young people who have difficulty determining the intentions of others may not, therefore, have been represented.

Furthermore, studies which were not published in English or where it was not possible to distinguish between the accounts of multi-informant participants were excluded from the present review. Important contributions may therefore have been missed. Finally, all studies in the current review reflected western populations with the majority of participants being white. This therefore limits the transferability of findings to other contexts as different cultures and ethnicities have been found to differ in terms of perception and response to victimisation (Sawyer, Bradshaw & O'Brennan, 2008).

1.4.2 Clinical Implications

Findings from the current review have important implications for services and professionals involved in supporting young people on the AS. A high number of young people reported that victimisation experiences had had a detrimental impact on their wellbeing, with many experiencing a direct decline in their mental health (Penney, 2013). Evidence suggests that childhood victimisation in the general population may have a long-term impact leading to continued use of mental health

services into adulthood (Evans-Lacko, Takizawa, Brimblecombe, King, Knapp, Maughan & Arseneault, 2016). This therefore has implications for teachers, parents and mental health services to work collaboratively to meet the unique needs of such individuals. A tendency among young people with autism to mask and minimise their experiences of victimisation coupled with difficulty in interpreting the intentions of others, may hinder their ability to communicate their needs and thus access vital support. Increased vigilance and awareness from support systems to reduce or prevent victimisation in this vulnerable population is therefore needed as previous literature suggests (Sreckovic, Brunsting & Able, 2014). In addition, addressing the phenomenon through training, development of policy and strategies to prevent victimisation may also serve to reduce its impact on currently over stretched health care and public-sector services.

A collaborative approach between educational and health settings which includes parents has been recommended in the literature with illustrative examples of best practice for reducing victimisation (Hong, Neely & Lund, 2014; Ttofi & Farrington 2011). The current review highlights a need for greater recognition of young people's resilience and the importance of developing their sense of agency rather than solely focussing on protection. Initiatives which have involved delivering educational programmes directly to young people on the AS to develop their skills (Beaumont & Sofronoff, 2008), employed peer-modelling based social skills training (Locke et al., 2013) and where the broader school environment has been the focus (Morewood, Humphrey, & Symes 2011) have proved effective in reducing victimisation.

Additionally, the majority of the reviewed studies explored the experiences of young people who had attended mainstream schools; young people from SEN settings perceived responses to victimisation to be generally effective. Where practicable, mainstream settings may benefit from employing strategies proven to be beneficial in SEN schools, however, it is conceivable that smaller classes and an increased ratio of staff to students may contribute to the success of such interventions.

1.4.3 Future research directions

The current review has highlighted the paucity of qualitative literature in this field and has illustrated the importance of the use of methodologies which gain an understanding of the subjective experiences of victimisation among young people on the AS. Four of the studies reviewed here explored the broader context of experiences of school for young people on the AS, suggesting a need for more narrowly focussed research to specifically explore first-hand experiences of victimisation and to learn more about how these young people cope with those experiences. Additionally, further exploration of young women's' experiences of victimisation is warranted to improve our understanding of gender differences. It is imperative that the wider context is considered in which women may risk 'flying under the radar' (Nasen, 2016) within educational, research and diagnostic contexts.

The systematic search methodology utilised for the current literature review yielded studies which reflected victimisation experiences during school years for young people, however, research suggests that people with autism may continue to experience victimisation throughout the life course (Jones et al., 2013). Further exploration of victimisation experienced during further/higher education or within

the workplace is therefore needed to determine the ongoing support needs of people on the AS post school.

Additionally, research suggests that young people on the AS may be perpetrators as well as victims of exploitation (Rose et al., 2015; Zablotzky et al, 2014). This was not the focus of the current review, however in a recent systematic review of quantitative studies, 10% of young people on the AS were found to be involved in perpetration (Maiano et al., 2016). Further investigation is therefore required to determine risk factors, possible motivators and consequences of young people on the AS engaging in victimisation behaviours.

1.5 Conclusion

Children and young people who are on the AS have been found to be at increased risk of experiencing victimisation. Research has mainly employed quantitative methodologies to determine prevalence rates and to investigate possible risk factors to victimisation for this population; however, the contribution of qualitative literature to gain an understanding of the lived experiences of young people has been recognised. The primary focus of the present review was therefore to critically evaluate the findings of qualitative literature which explored the experience of victimisation from the perspective of children and young people who are on the AS. Findings revealed that victimisation is a complex, idiosyncratic experience for young people on the AS with multiple factors influencing coping or support seeking responses including traits related to autism, possible gender differences and perceived efficacy of strategies. Development of interventions which involve parents, peers and a whole school approach to prevention whilst fostering autonomy

for young people is recommended. More focussed future qualitative research is suggested to inform clinical and educational interventions, and to more fully understand and address the specific experiences and needs of this vulnerable group.

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Chapter 2: Empirical Paper

***“I’m vulnerable; don’t get me wrong, I’m vulnerable”*: An exploration of the experiences of young women on the Autism Spectrum entering into a romantic relationship.**

Written in preparation for submission to *Autism & Developmental Language Impairments*

(See Appendix C for guidelines)

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2.0 Abstract

Background: Young adulthood is a critical period in the development of sexuality; however, research that focuses on how intimacy is experienced by people who are on the Autism Spectrum (AS) is limited. Despite recent evidence suggesting that young women on the AS are vulnerable to experiencing victimisation, research has focussed more on the perceptions of secondary sources to gain an understanding of the experiences of this group. **Aim:** The present study aims to investigate the lived experience of romantic relationships for young women on the AS. **Methods:** Interpretative Phenomenological Analysis (IPA) was utilised to analyse the data of five young women (18-31) who took part in semi-structured interviews. **Results:** Findings revealed three superordinate themes: ‘Navigating Ambiguity’, ‘Identifying Vulnerability’ and ‘Constructing the Future Self’. **Conclusion:** The findings served to broaden our understanding of the needs of this client group to guide future clinical support. Directions for further research and limitations are discussed.

Keywords: *Autism, young women, romantic relationships, experiences, Interpretative Phenomenological Analysis.*

2.1 Introduction

2.1.1 Autism in context

There are approximately 700,000 people on the Autism Spectrum (AS) living in the United Kingdom (UK; The NHS Information Centre, 2014). People on the AS often experience difficulties in social functioning that can affect their capability to relate to the thoughts and feelings of others, in addition to challenges associated with social reciprocity, flexibility of thought and sensory differences (APA, 2013; Attwood, 2006). Difficulties in social reciprocity may lead to a lack of peer relationships which research suggests may correlate with psychological distress including increased depression and anxiety (Mazurek, 2013) and reduced quality of life (Jennes-coussens, Magill-Evans & Koning, 2006). Furthermore, it is estimated that one in three adults who are on the AS experience severe mental health difficulties due to unmet support needs (Rosenblatt, 2008).

2.1.2 Autism and gender differences

Despite an increased awareness of the needs of individuals on the AS, our understanding is incomplete (Barnhill, 2007). Existing research has focussed mainly on the experiences of men and the majority of studies which include women have been mixed sex samples making the specific needs of females unclear (Tobin, Drager & Richardson, 2014; Nichols & Blakeley-Smith, 2010; Stokes & Kaur, 2005). The predominant focus on males with autism may be attributed to the higher ratio of men receiving a diagnosis (Watkins, Zimmerman & Poling, 2014) with a recent systematic review and meta-analysis of prevalence studies, suggesting that the ratio is closer to 3:1 than the previously assumed 4:1 (Loomes, Hull & Mandy, 2017).

A diagnostic gender bias is reported to exist suggesting that females may be at risk of not meeting criteria for autism with differences being mislabelled or missed entirely (Lai & Baron-Cohen, 2015). Furthermore, tools utilised for diagnosis may, themselves, be gender biased (Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015). Research suggests that females may utilise different strategies to males to manage their social environment including masking or adapting behaviour through imitation of their peers; hence difficulties being underreported, and support consequently not provided (Bargiela, Steward & Mandy, 2016; Tierney). In addition, females have been found to internalise behaviours when compared with the male population which may increase their risk of developing difficulties with their mental health, including anxiety and depression (Mandy, Chilvers, Chowdrey, Salter, Seigal & Skuse 2011).

2.1.3 Romantic relationships and autism

Research suggests that adults who are on the AS have the desire to enter romantic relationships (Gilmour, Schaloman & Smith, 2012) and demonstrate the same level of interest as their ‘neuro-typical’ peers (NT; Moreeno, Wheeler, Parkinson & Attwood, 2012). This suggests that challenges in social skills, rather than a need for solitude, may lead to difficulties in forming and maintaining romantic relationships.

A lack of experience of forming friendships due to limited contact with peers may prevent individuals who are on the AS from learning skills required to form romantic relationships (Prendeville, Prelock, & Unwin, 2006). Difficulties in emotional regulation, flexibility of thought and sensory differences may further impede individual’s attempts to establish them (Urbano, Hartmann, Deutsch, Bondi Polychronopoulos, & Dorbin, 2013).

Muller, Schuler and Yates, (2008) found that participants with AS reported social isolation and a longing for greater intimacy. Qualities needed to understand and maintain intimate relationships have been found to be the exact traits thought to be impaired in individuals who are on the AS (Tarnai & Wolfe, 2008). Erikson (1985) and other developmentalists, stress the importance of establishing and maintaining relationships with romantic partners for emotional wellbeing. A recent study suggested that 59% of participants who were on the AS were single but had been in relationships previously. However, 41% of participants had never been in an intimate relationship that had lasted longer than three months (Byers, Nichols & Voyer, 2013).

Adults on the AS have been found to be at increased risk of experiencing victimisation due to social isolation, lack of sexual knowledge and reliance upon others (Brown-Lavoie, Viecili & Weiss, 2014). Individuals on the AS have reported safety concerns regarding dating with 81% of participants in a recent survey indicating safety fears regarding meeting people online (Roth & Gillis, 2014). Research findings support the accuracy of such concerns with 16-25% of adults on the AS reporting having experienced sexual abuse (Chan & John, 2012). Furthermore, young women have been found to be particularly vulnerable and at risk of being sexually or emotionally exploited (Cridland, Jones, Caputi & Magee, 2013).

In a recent study examining the experience and interest in romantic relationships of adults on the AS, over half of the participants expressed concerns regarding how to find a partner, not knowing how a relationship works and a fear of not being capable of fulfilling a partner's demands (Strunz et al., 2016). Despite desiring a romantic

relationship, participants who were single described contact with others as exhausting; indicating potential barriers to individuals being able to cope with the demands of romantic relationships.

2.1.4 Qualitative research exploring the experiences of women on the AS

Previous studies have focussed on the accounts of caregivers of young people who are on the AS, rather than the person with the condition, to gain an understanding of their experiences (Farley et al, 2009; Byers, Nicholls, Voyer & Reilly, 2012).

Furthermore, the majority of studies exploring romantic relationships for individuals on the AS, have utilised quantitative methodologies.

The importance of ensuring that the voices of individuals with developmental differences are heard has been recently reflected in the field of autism research (Bolte, 2014). The unique challenges faced by women on the AS, and the underrepresentation of females in the literature, have led to an increase in the use of qualitative methodologies to explore the perspectives of ‘experts by experience’ (Bargiela et al, 2016; Tint & Weiss, 2017). The particularly challenging and complex period of adolescence has recently been recognised as increasing the demands placed upon girls who are on the AS in navigating their social world (Cridland et al., 2013). Cridland et al’s (2013) study was the first of its kind to explore the experiences of adolescent females who have autism, however, narratives were co-constructed with the mothers of participants, which further highlighted the need for the voice of the young person to take precedence.

Despite focussing more generally on the female autism phenotype, experiences within romantic relationships emerged as a significant theme within Bargiela et al’s

(2016) recent qualitative study. Young women reported experiences of victimisation within relationships, with particularly high incidence of sexual abuse.

2.1.5 Rationale for the present study

To date, little is known about experiences of entering romantic relationships and the potential buffers to pathological distress among young women on the AS. Despite young adulthood being a critical period in the development of sexuality, research that focuses on how intimacy is experienced by young people on the AS, is limited. Evidence suggests the potential vulnerability of women to victimisation; however, research has focussed more on the perceptions of males and carers to gain an understanding of the experiences of young women on the AS which limits our understanding of the phenomenon to the views of others. Gaining an understanding of how young women experience romantic relationships is likely to provide greater insight into the issues of isolation, victimisation and wellbeing and provide cues for future support needs by giving voice to their unique perspective on their own experiences.

2.1.6 Aim

The aim of the present study is to investigate the lived experience of entering into romantic relationships for young women who are on the AS. By adopting a phenomenological perspective, it is anticipated that the current study will serve to broaden our understanding of the needs of this group to guide future clinical support.

2.1.7 Choice of language

There is currently much debate regarding how best to conceptualise autism; discussion and disagreement exists amongst people who have autism, their family members and the scientific population which, in part, reflects the growing changes in disability rights and neurodiversity movements (Kenny, Hattersley, Molins, Buckley, Povey & Pillicano, 2015). Researchers have an ethical duty to utilise terminology which reflects the preferences of the individual. The young women who took part in the present study had received a diagnosis of either Asperger's Syndrome or Autism Spectrum Disorder (ASD) however, when asked at interview, reported their preference for the term autism when describing themselves; this term will therefore be utilised along with AS as favoured by the autism community (Kenny et al. 2005).

2.2 Method

2.2.1 Research Design

A qualitative approach was deemed the most appropriate due to the exploratory nature of the research aims. Interpretative Phenomenological Analysis (IPA) was selected due to its focus on determining the perspective of the 'insider' in order to gain a sense of how participants view and make sense of their personal world (Smith, Jarman & Osbourne, 1999). A double-hermeneutic process, which involves the researcher making sense of the participant making sense of their experiences, defines IPA's idiographic perspective (Smith, Flowers & Larkin, 2009). Central to the philosophy of this methodology is the focus on the lived experience of the individual. Through interpretation of the accounts of such experiences, meaning and thus understanding of phenomena, is gained as a result (Martins, Walker & Fouche, 2013).

2.2.2 Participants

In line with the primary concern of IPA methodology to obtain an in depth, detailed account of individual experience, a small, purposive, sample was favoured (Smith et al., 2009). Participants were assessed for eligibility against inclusion and exclusion criteria as outlined in Table 2.1.

Table 2.1 Participant Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Gender	Female	Male
Diagnosis	Identified as receiving a diagnosis of autism.	Awaiting or undergoing assessment. Identified as not receiving a diagnosis of autism.
Interest	Expressed an interest in entering into romantic relationships.	Did not express an interest in entering into a romantic relationship.
Relationship status	Identified as being single.	Identified as being in a relationship.
Age	18-35	<17->36
Language	English speaking	Non-English speaking

The age range of 18-35 was chosen as this is recognised as an important milestone in sexual development however the upper limit reflected the potential for young women on the AS to develop at a later stage to their peers (Henault, 2006). The decision to exclude women who were undergoing assessment or did not have a diagnosis was based on the need to maintain homogeneity. Only women who identified as having an interest in romantic relationships were included to ensure that their position was in line with the research aims. Those who were currently in a relationship were excluded as their experiences may be differ from young women on the AS who

demonstrate an interest in romantic relationships but are single. Five young women were recruited for the study from a social group for adults on the AS. Demographic details and characteristics of participants are detailed in Table 2.2. Specific details have been generalised and pseudonyms given to preserve anonymity.

Table 2.2 Participant characteristics

Participant	Age	Ethnicity	Age at diagnosis	Employment status	Sexual orientation
Jo	*Age range: 18-31	* White British	*Age range: 7-31	*All participants identified as being either employed or a student.	Heterosexual
Sam					Heterosexual
Chloe					Heterosexual
Lisa					Did not know
Amy					Heterosexual
Mean	22		16		

*Specific demographic details not identified to ensure anonymity

2.2.3 Procedure

2.2.3.1. Ethical procedures

The research was conducted in line with the recommended ethical guidelines of the British Psychological Society's Code of Ethics and Conduct (BPS, 2010). Ethical approval was sought and approved by Coventry University's ethics board (Appendix D).

2.2.3.2 Materials

A semi-structured interview schedule was developed in line with IPA guidelines (Smith et al., 2009) to address the research aims. Through consultation with the research team, the founder of the social group for individuals on the AS and

literature in the field of autism, interview questions were produced and agreed upon (Appendix H). Open-ended questions were chosen with the intention of stimulating reflections on personal experiences, thus avoiding the potential for ‘yes’ or ‘no’ answers.

2.2.3.3 Recruitment

Recruitment was achieved through a well-established social group for individuals on the AS following previous contact with the founder of the organisation (Appendix F). Details regarding the study aims and the participant information sheet (Appendix G) had been sent to the founder who agreed for me to visit the social group to discuss further and gauge the interest of group members. In order to establish trust and become familiar to members, it was agreed that I would attend the group on a regular basis; literature suggests that the development of a rapport with people on the AS is important to increasing accessibility to participation in qualitative research (Fayette & Bond, 2017). Upon attendance, female members were approached by the lead researcher or founder and provided with an information sheet and contact details. Those who were interested in participating were invited to contact the lead researcher or the founder of the group to arrange an interview which took place at the centre; an environment that was deemed appropriate due to being familiar to participants. The option for interviews to take place at a preferred location was also provided.

2.2.3.4 Interview procedure

Participants were provided with the opportunity to re-read the information sheet and to ask any questions or discuss any concerns regarding participation prior to providing written consent (Appendix H). Demographic details were gathered, and all interviews commenced at the social group centre (Appendix J). Each interview was

audio-recorded and ranged in length between 26 to 65 minutes (mean= 45 minutes). Upon completion, participants were reminded of their right to withdraw from the research within a specific time period, as detailed in the consent form. A verbal debriefing and a written version (Appendix K) were provided with details of local support services; more imminent sources of support were discussed when needed, including identification of a staff member from the group due to the emotional impact of participation.

2.2.4 Analysis

Following completion of each interview, audio-recorded data was transcribed verbatim with any identifiable information omitted or assigned a pseudonym; all audio data was destroyed upon completion of transcription. Data was analysed in keeping with Smith et al.'s (2009) inductive IPA methodology (Appendix L). The process of analysis is demonstrated with the use of excerpts from one transcript to present coding (Appendix M) and theme development (Appendix N). In line with Smith et al.'s (2009) recommendations for the emergence of themes across transcripts, participants were assigned a colour to aid immersion in the data and lead to the construction of superordinate and subordinate themes.

2.2.4.1 Validity of analysis

The importance of promoting the validity of qualitative methodologies through employment of quality control measures is now widely recognised in the literature (Reynolds, Kizito, Ezumah, Mangesho, Allen & Chandler, 2011). Credibility criteria outlined by Yardley (2000) were considered and adhered to throughout each stage of the research process for the current study.

Debriefing with the research team occurred at regular intervals and feedback was consistently provided; this enabled a fresh perspective and aided interpretation of the data. Challenging any assumptions made by the lead researcher consequently increased credibility of findings and their likelihood of being substantiated from the data. Furthermore, a peer was employed to code a single transcript to reflect on and determine any converging or diverging findings within the data.

2.2.4.2 Researcher position

The lead researcher, a Trainee Clinical Psychologist, had no prior contact with the organisation from which participants were recruited, however, (as detailed in section 2.2.3.3) had visited the group on a regular basis outside of scheduled interviews to develop a rapport prior to recruitment. In line with IPA's emphasis on reflexivity, rather than objectivity, which accepts that the researcher is part of the world they are researching, a reflective diary was kept, and a bracketing interview also took place with a peer who was familiar with IPA. This process served to "increase objectivity and amplify the researcher's own reflexive capacity" (Rolls & Relf, 2006; p. 286).

2.3 Results

Three superordinate themes emerged upon completion of the data analysis. Each of which were comprised of a number of subordinate themes and are detailed in Table 2.3. Themes and corresponding subordinate themes are detailed and discussed, with reference to the emergence of converging and diverging findings.

Table 2.3 Superordinate and subordinate themes

Superordinate theme	Subordinate themes
Theme 1: Navigating ambiguity	<p>“Like, what is it?”</p> <p>“I was confused more than anything”</p> <p>“I’m not me”</p>
Theme 2. Identifying vulnerability	<p>“I hated it but I did it anyway”</p> <p>“I wanted to be kind of normal?”</p>
Theme 3. Constructing the future self	<p>“Just a bit more <i>always</i> worried about it”</p> <p>“If I’m not ready, I’m not ready”</p> <p>“Acceptance is all I <i>mainly</i> want”</p>

2.3.1 Navigating ambiguity

All five young women reported experiencing varying degrees of confusion regarding the ambiguous nature of romantic relationships. Uncertainty was expressed in relation to what constitutes and defines a romantic relationship: ‘Like what is it?’, the unfamiliarity of new feelings: ‘I was confused more than anything’ and of adaptations made to the self: ‘I’m not me’.

2.3.1.1 “Like, what is it?”

All participants reflected on their uncertainty regarding what defines a romantic relationship and whether their experiences warranted or justified this title. Jo, Sam and Chloe expressed a perceived concern that their relationships had not been “proper” which they attributed to a variety of reasons. For Chloe, despite defining

her experiences as “obviously” relationships, her expectations and how she was treated within these, for her, did not warrant the full definition:

Erm, I wouldn't really call them romantic or proper relationships because, obviously they were classed as a relationship, like I had a boyfriend, well two boyfriends, but they were both horrible (Chloe, L- 160-162).

Sam, however, described an intense feeling of frustration as her expectations for a romantic relationship could not be fulfilled due to her mental health and reflected on how this prevented her from achieving what others were able to:

Well it makes me think that I'll never have a proper relationship with somebody because my mental health will just get in the way like my over worrying, my overdoing things, under doing things, just saying the wrong thing or doing the wrong thing. It just makes me think it won't ever work and it sort of makes me feel frustrated (Sam, L-106-110).

Sam's list of personal behaviours in relationships appeared to have reduced her sense of agency; the outcome, for Sam, appeared inevitable. The cyclical nature of her emotions being both a barrier to experiences and declining further as a consequence highlighted this further.

In addition to confusion being experienced regarding what was “proper”, for three young women, understanding why people enter romantic relationships and how this was achieved was difficult to comprehend. A sense of urgency was conveyed through participants' questioning within their narratives as demonstrated by Chloe:

That's what I mean by trying to read people, like what is it? I mean obviously, family's family but is it a best friend? Or is he something more? (Chloe, L-310-312)

The rhetorical nature of Chloe's account highlighted her mounting sense of unanswered questions and perhaps participants' need for the uncertain to be made certain. Furthermore, Chloe, Lisa and Amy attempted to reify romantic relationships, demonstrated through their use of the pronoun 'it'; perhaps through construction of the phenomenon as an entity, they felt better placed to understand it:

*I guess I find it confusing how people manage to get in to them, how **it** is, what exactly is **it**? (Amy, L-428).*

Both Sam and Chloe engaged in a sensemaking process which involved reflecting upon their current and past relationships. Struggling to determine what separates platonic relationships from romantic, Chloe reflected on becoming "mixed up" when enjoying an individual's company whereas Sam questioned whether it was an extension of the parental relationship; both reported fearing isolation and viewing romantic relationships as a possible buffer to this:

For starters I'd have to really think about how I feel because I know I can get mixed up with liking someone's company and actually liking them as a person, do you know what I mean? Like really liking them. (Chloe, L-265-268)

A need for clarity of understanding and lack of knowledge were experienced as barriers to accomplishing a desired romantic relationship for the young women, appearing to be seamlessly achieved by others. Lisa, for instance, reflected on the limited use of observation to improve clarity:

I: Do you see other people in relationships and...

Lisa: (Over question) I'd love it yeah. Er, I watch, and I think that would be so cool, but I don't, I don't really understand it (Lisa, L-358-361)

2.3.1.2 “I was confused more than anything”

For all participants, confusion was identified as the main feeling surrounding their experiences of and was often accompanied by anxiety. For Jo and Sam, experiencing attraction was unfamiliar and frightening, however a combination of feelings was found to occur:

I would say happy and stuff but also very insecure and uncertain and I actually felt very scared. I'm not sure if it was even in a bad way but I felt scared (Jo, L-68-70).

Jo appeared to be making sense of what she had perceived to be emotions which were either positive or negative extremes and how, within this new experience, they had become blurred. Jo's emphasis on her uncertainty as to whether the fear was in fact “bad” demonstrates her confusion. Sam echoed Jo's experience when describing the physical sensation, she encountered and her difficulty articulating such feelings:

I once felt sick to the stomach which felt a bit weird but other than that I don't know, it's hard to explain. Mainly sick to the stomach. (Sam, L-226-227).

A sense of loss was also expressed regarding missed opportunities due to difficulty identifying, understanding and consequently misinterpreting the unfamiliar feeling of attraction. Some women reflected on “not act(ing)” on their attraction due to not knowing “what was happening” and thus awareness was delayed:

Someone I was friends with, I just felt attracted but I didn't even know it at the time and then it was only when I think back that I think, yeah, I probably was (Jo, L-205-206).

A significant experience for half the participants was anxiety or ambivalence regarding the physical and sexual nature of romantic relationships. Sam expressed feeling perplexed when “everybody was going on about it” and described it as “so great” when this did not match her own experience. An extract from Chloe’s narrative illustrates the potential pressure she feels from society:

I mean, obviously, it's, apparently, become a big thing now, like everybody's doing it and I'm like...Ok! (Chloe, L-339-341)

Chloe’s use of the words “obviously” and “apparently” may represent the discord between herself and society; her perception of “everybody” having sex suggests her vigilance to an activity that she does not yet feel ready for as she went on to explain in her account. For several participants, having to rely on how they imagined sexual experiences to be was described. Furthermore, Jo attributed her anxiety to characteristics associated with her diagnosis:

I'm not always fantastic with contact, people touching me and also the struggling to predict what's going to happen, like if I had sex with someone and if I got pregnant and what would happen in a relationship and all that. I struggle to think about it and predict it and yeah, I reckon most of that is, I don't want to blame it on Asperger's but a lot of that is probably to do with it. (Jo, L-283-287).

Conversely for Amy, confusion was a result of disillusionment with her experience of a sexual relationship; what she had perhaps been expecting from societal

influences combined with a lack of experience or knowledge was a difficult experience in reality:

So, I had erm, slept with him. It was confusing because, I dunno, it was very painful, but I didn't really know what it was supposed to be like (Amy, L-352-353).

In addition, interpreting the intentions of others was a pertinent cause of confusion for over half the participants. Chloe described being called an offensive name “as a joke” by her peers and expressed bewilderment at their intentions:

I got called a slag and stuff, as a joke, but it's not funny... I mean I find it funny that the real definition is obviously dirty waste, it don't mean you sleep with someone! (Chloe, L-193-197).

Chloe's apparently literal interpretation illustrates the challenges that she, and other participants, face in attempting to navigate a complex social world. Furthermore, the assumptions made by others regarding their understanding of intentions, exacerbated participants' feelings of confusion and distress:

He said he thought that we were just messing around and I kind of wanted to understand how he thought that I'd know (tearful) if he didn't tell me? (Amy, L-372)

Amy elaborated on her need for the perceptions of others to be made concrete by seeking advice in order to know “how you're supposed to tell if someone is being honest” and why being honest herself did not lead to a reciprocal response.

2.3.1.3 “I'm not me”

Four participants reflected on their experiences of masquerading and its impact on past and future romantic relationships. Lisa described “cop(ying)” her peers reports

of experiencing attraction but “didn’t get why” suggesting that she did not understand why they were commenting but more importantly why they were experiencing it; additionally, Lisa reflected on perceiving there to be “a big gap” between her and others, suggesting her attempts to reduce this, had not proved fruitful. Conversely, Sam described the pressure placed on her by others to change in order for romantic relationships to “work a little bit” and how this had impacted on her identity:

I have to keep changing everything, what I do, how I say it, what I say; it just makes me feel like I’m changing into somebody else and I’m not me (Sam, L-175-176).

Sam’s description evoked a sense of impending permanency of the mask; the intended temporary nature of the changes had a transformative effect which had overridden her true self. Internal conflicts appeared to exist for all participants who reported masking behaviours in their attempts to ‘bridge the gap’ between themselves and others.

For Jo and Amy, a fear of appearing fraudulent within romantic relationships was reported. Amy described polarising two parts of her identity, one which existed when outside of the house and was “better at behaving” in a “normal” way and the other existed inside and appeared more “autistic”. The potential for a future romantic partner to witness both sides evoked anxiety:

When I’m at home, I guess my behaviour can be seen more autistic, so I’d worry that someone might get to know the person who I can be but then not like the kind of autistic bits (Amy, Lines- 494-497).

Amy's account suggested a belief that an inauthentic-self would be most likely to be accepted by another, whereas the potential for her autistic-self to be 'found out' may lead to rejection. This represented a dilemma for both Amy and Jo who desired acceptance but feared the consequences of being truly 'seen' by a romantic partner. Reference was made to their ability to suppress this 'side' on a short-term basis; however maintaining this long-term would not be possible:

They will probably see stuff which they have never noticed before just from going on dates and they would have it all the time, whereas not being able to get rid of it (Jo, L-332-333).

Jo's belief that a future partner may wish to 'get rid' of her autistic 'side' further emphasised her fear of being rejected; the paradoxical nature of masking behaviour was undoubtedly clear in both accounts.

2.3.2 Identifying vulnerability

Victimisation and mistreatment were, sadly, experienced and reported by all participants. Each young woman attempted to make sense of these experiences and identified possible causal factors including vulnerability, naivety and a desire to 'fit in'.

2.3.2.1 "I hated it but I did it anyway"

Experiencing the need to please or to meet the demands of others was a common theme reflected in all accounts. Both Jo and Chloe described an awareness of being easily "pushed into" doing things which illustrated the involuntary nature of their participation. For Jo, "somebody really, really want(ing) to" do something would persuade her to engage in behaviours that she did not feel ready for. In addition, Chloe insightfully reflected in her narrative "I'm vulnerable, don't get me wrong,

I'm vulnerable" which signified that, despite attempts to rectify this, was an inherent characteristic:

I used to go around kissing boys and stuff like that and that's because they wanted to and I didn't at all. I felt like I had to repay them for some reason and because they're showing their affection, they're flirting with me and stuff. (Chloe, L-346-349).

The term "repay" may imply that a debt was owed, despite wanting to say no, Chloe reported fearing "what's going to happen if I don't?". A lack of reciprocity was a common experience reported by participants including relationships which had centred around the needs of the other:

It wasn't the best relationship; I think I just looked after her really. I just supported her a lot and did everything for her (Lisa, L-171)

In a similar vein, Sam described experiencing an ultimatum which involved either having to subordinate her own needs, or risk being rejected:

I've had relationships in the past where they were very much 'I'm boss, you do what I want, it's my way of thinking or the highway'. (Sam, L-300-301).

In line with Sam's reflections, a desire for friendship and fear of missed opportunity for connection was also attributed to agreeing to the ideas of others for the young women. A fear of "ruin(ing)" illustrates the importance placed on establishing relations with others and the tendency to blame oneself:

I didn't want to ruin the opportunity because, I don't know, I thought I was making friends, so I did it anyway. (Amy, L-358-359).

A sense of helplessness was felt by participants who had experienced abusive relationships. Chloe, poignantly, reflected on her past and how, despite “hating” what was done to her, felt paralysed within her position:

I’ve sort of felt easy and I’ve sort of felt helpless? Like I had no voice and I had no say in anything, like I just felt I had to do what other people wanted...letting them touch me and I hated it (Chloe, L- 492).

Helplessness was also felt by Lisa, who described turning to substances so that she “didn’t know what (she) was doing”. A need to anaesthetise herself from the reality of the experience was illustrated:

Lisa: I drun..., I used to get drunk to erm to do it, he didn’t drink so I, yeah.

I: And how often did that happen?

P: A lot (laughs) (Lisa, L-279-284).

Perceiving the other to be ‘right’ and the self ‘wrong’ was experienced by several participants. For example, Amy, described being “thumped on the back” by a previous boyfriend and suggested that this was due to her saying “something wrong”. Similarly, Amy reflected that she had done what she had been told to do because “(she) had assumed that that was right”:

He didn’t like to use things, so I ended up with chlamydia. I’d kind of expected that I would be more able to say stuff but because he was the one with experience, I didn’t want to look stupid. (Amy, L-361-364).

For Jo, the nature of her experiences had felt too painful to share with others, thus preventing her from gaining support:

Sometimes I talk to someone about it, it depends, sometimes I don't want to or feel ready to. Other times I'm guilty of just blanking it out and not thinking about it because it's too difficult (Jo, L-227-229).

In contrast, Chloe reported wanting support from others, however intense fear prevented her from seeking this; reliance upon the actions of others enabled change:

I didn't report it to a teacher, but my friend did, and I know who it was because the day before she reported it she said "Chloe, tell him to stop!" and I was like, I want to but I can't. I was so afraid of him, I was scared of him (Chloe, L-233-236).

2.3.2.2 "I wanted to be kind of normal"

Sam, Lisa and Amy reflected a desire to fit in within society and identified this, when making sense of their experiences, as a vulnerability factor within romantic relationships. For Sam, "normal" was based on her friends being in relationships which caused her to look introspectively:

I've got loads of mates in relationships or moving in with somebody and then there's just me, still living at home at the age of (), not seeing anybody, not really doing much and it's not really healthy if that makes sense (Sam, L-140-142).*

Sam's description suggests that she perceives her reality as less healthy than that of her peers, therefore, increasing the distance between herself and others. She reflected further that her fear of being perceived as abnormal acts as a barrier to her entering into new romantic relationships:

How should I word this? (pause) I'm worried that they're gonna get bored because they'll find someone better, someone normal (Sam, L-193-194).

Lisa and Amy shared similar reflections regarding how they had entered into relationships that had been detrimental to their wellbeing in order to feel “normal”. Lisa described having “no idea” how a relationship had started with a previous boyfriend but reported thinking that “that’s what people did”. She reflected further on a sense of relief when entering into her first relationship:

I suppose I was relieved a bit because I was like oo, erm, I was quite happy to just feel like I fitted in (Lisa. L-155).

Amy described a similar experience when engaging in sexual intercourse for the first time:

Although I didn’t like it and I wanted it to stop, I didn’t do anything, and I think I wanted to be kind of normal? Do what other people do (Amy, L-355).

For Amy and Lisa, it appeared that the desire to engage in behaviours perceived to be “normal” was worth the risk of encountering situations which were alien and anxiety provoking. The longer-term consequences of this however, had been unexpected and had led Amy to question what normality actually meant:

It’s quite hard to know what’s normal and what is kind of... hard to know how to say what you do and don’t want (Amy, L-562).

2.3.3 Constructing the future self

All participants reported a sense of what they wished for their future self in terms of how their experiences had maintained or changed their perspectives, how they viewed and managed risk and what qualities they desired in a future partner.

2.3.3.1 “Just a bit more *always* worried about it”

Experiencing a range of events which had impacted on mental health and self-esteem, all participants reflected on a process of evaluating advantages and disadvantages to entering into future romantic relationships. For instance, Jo reflected on the lasting emotional effects of an “obsessive” relationship:

I’ve just been really scared of the whole process basically and to be honest with you I still am (Jo, L-144-145).

However, the potential benefits of romantic relationships appeared to prevail despite requiring adjustment:

I might struggle with the change, yeah to start with I’d struggle with change but once I got over that hurdle I reckon it would probably be better (Jo, L-429-431)

A similarly evaluative process was evident in Sam’s account:

It’s easier to be single because then you don’t have to worry about upsetting somebody else, but I would like to, if I ever got the chance again (Sam, L-293-294).

Sam’s perception of single life being “easier” perhaps demonstrates her perception of a comfortable existence in which the likelihood of distress is reduced; however, she recognises that being in a relationship in a relationship is something she values more.

The potential to experience isolation as a result of unsuccessful relationships, however, continued to cause concern for two participants. Sam questioned “what’s going to happen next?” following the breakdown of a relationship and explained

how, for individuals on the AS, coping with loss requires more than simply “hav(ing) to get the ice cream out”. In a similar vein, Lisa described the ending of a relationship leaving her feeling “sad, angry and confused” which culminated in the additional loss of her social network:

She was the one who arranged a lot of the group things...so I thought, I have lost, and I did at that time, I didn't have anyone (Lisa, L-207).

2.3.3.2 “If I’m not ready, I’m not ready”

All participants shared reflections on personal growth and resilience following their experiences which involved development of strategies to protect themselves from risk and identification of support needs.

Four participants reflected on effective ways to manage their feelings of vulnerability including preventing contact with individuals who caused them distress. Lisa recalled deciding “I don’t like this, so I’m not doing it anymore” due to feeling as though she was no longer coping with the dynamics of the relationship. Jo, however, reported that stopping contact when a previous boyfriend had become “obsessive” was the only viable option:

I just kind of had to cut him off which wasn't fantastic because he was also a good friend beforehand, but I didn't know how else to deal with it. (Jo, L-61-62).

Amy reflected a similar experience:

So it was when I found out that he had given me an infection, that was when I decided that I would block him because for some reason I kind of assumed that,

whatever the situation was, he wouldn't have not used anything if he wasn't 100% sure (Amy, L-391-395).

The utilisation of “cut(ting) off” and “block(ing)” portray a physical removal of the presence of the damaging other and highlight the urgency for distress to be detached from the young women.

Within participants' sensemaking process, the identification of support needs was apparent including the lack of available information regarding sex-education and romantic relationships:

I guess it would have been helpful to know what a healthy relationship looked like from the inside not just what it appeared like looking at it and knowing maybe what you should expect from someone and how they treat you and maybe better education about how to stop things that you don't want (Amy, L-574-578).

Amy's reflection suggests that from her past experiences she had gained an awareness of a relationship appearing “healthy” yet, internally, being experienced as abusive and disrespectful. Jo mirrored Amy's request for clearer and more readily available information in her account:

There doesn't seem to be any help for it and I know it's a private thing but there are also people who don't understand it like me- (Jo, L-317-319).

Jo's description of romantic relationships being a “private thing” suggests that discussing the phenomenon is a taboo; perhaps this indicates the young women's fear of being inappropriate and therefore potentially rejected by others. Censorship of discussions of a sexual nature may therefore have acted as barrier to education for some participants. Similar reticence is illustrated in Chloe's account:

I think before I (whispers) have sex I might wanna plan it out a little like obviously get the pill and stuff (Chloe, L-355-359)

Chloe's decision to "plan" out her first experience of sexual intercourse illustrated how unhealthy past experiences had shaped participants' approach to new relationships. For others, priorities had changed as a consequence, with their own needs taking precedence:

You've got to think about what's best for you and what's best for your health, your emotional state, your social life, your everything really. (Sam, L-287-289).

Personal growth was also evident in Amy's account when reflecting on how she would "worry less about what was normal" in future and placed emphasis on what she was comfortable with:

Don't do something because you think you should do it but because you want to do it and you can stop things if they become too painful (Amy, L-463-465).

Furthermore, Chloe reflected on a cognitive shift regarding her fear of saying no to future partners:

But now, one day, I thought well what's going to happen if I don't say no? Exactly. It's much worse if you don't tell somebody. (Chloe, L-431-432).

2.3.3.3 "Acceptance is all I mainly want"

A need to feel fully accepted by a future partner emerged as a prominent factor and was shared by all participants. Jo described wanting to find someone who "likes me for who I am" which was mirrored in an extract from Sam's account:

It's very difficult to find someone that understands enough to put up with our craziness (laughs) (Sam, L-126-127).

Despite acceptance emerging as the most desired feature, a variety of qualities were reported by participants. For the majority, physical appearance and the sexual element of romantic relationships were secondary to personality and whether “they’re a nice person”, as illustrated by Chloe:

Cos it's not just about attraction and it's not just about (whispers) sex either, it's about trust, it's about feeling safe and sort of becoming a better person (Chloe, L-394-396).

Several participants described companionship as a factor which formed part of their interest in a romantic relationship with reference to the impermanence of family:

I just like the idea of having people who care about me and I care about them. You know, sadly when my parents aren't here anymore then I've got people around me that I trust and stuff. (Jo, L-342-345)

Finally, trusting a partner to have good intentions was, understandably, reported as a vital quality given the abusive experiences that the young women had encountered.

This was, however, reported as requiring time to achieve:

I've got to be comfortable first. Like, I'd wait 12 months if I had to, just to be comfortable (Sam, L-200-201).

An aspiration for romantic relationships to develop participants personally was reported as an equally important factor. Amy described hoping that a relationship

would increase her confidence to “go out and do things” which would additionally help her to “feel less lonely”. Similarly, Chloe described desiring a relationship in which reciprocal growth occurred:

I don't know much about relationships, but I know part of it is making each other better like encouraging and you know inspiring, stuff like that (Chloe, L-252-255).

2.4 Discussion

Three superordinate themes emerged from the study which will now be discussed alongside clinical and research implications and limitations.

2.4.1. Navigating ambiguity

This superordinate theme captured the degree of uncertainty and ambiguity experienced by participants. Women in the current study expressed motivation for a relationship of this kind however, barriers to understanding, due to autism related differences led to frustration. This suggests that traits associated with autism may impede people on the AS's ability to establish romantic relationships (Urbano et al., 2013). Furthermore, all participants reported experiencing difficulty forming friendships during childhood and adolescence, which research suggests may impede young women in the development of important skills required to form romantic relationships (Prendeville, Prelock & Unwin, 2006). Such absence of opportunity to develop the social and emotional skills required for friendships suggests a developmental trajectory to participants' difficulties within romantic relationships, with earlier friendship-forming difficulties potentially influencing how successful later attempts to form friendship or romantic relationships will be. This finding is consistent with existing research which indicates that for adolescents with

disabilities, victimisation is less likely to occur within relationships for those who have developed greater social skills (Sterzing et al., 2012).

Some young women experienced heightened anxiety as a consequence uncertainty within romantic relationships. Environmental unpredictability is strongly correlated with anxiety for diverse populations but is particularly prevalent in people with autism (Sinha, Kjelgaard, Gandhi, Tsourides, Cardinaux, Pantazis, Diamond & Held, 2014). The need to impose sameness to mitigate this anxiety appeared to create a dilemma for participants who were motivated to establish a romantic relationship but their unpredictable nature exposed participants to difficult emotions. Furthermore, several participants described difficulties related to the physical, sexual element of romantic relationships including experiencing discomfort and anxiety regarding the prospect of close contact. This may relate to sensory dysregulation, a criterion of autism that was included in the DSM-5 (APA, 2013) and is consistent with previous research which found that sensory overload, pain and a delayed ability to communicate discomfort during sex was reported by participants on the AS (Pewell Barnett & Maticka-Tyndale, 2015).

Adapting the self to 'fit in' with societal expectations was recognised as a paradoxical experience for participants. Despite sophisticated imitation and masking behaviour enabling them to feel accepted by others, fear of rejection once their true identity was revealed was expressed. The disadvantages of masking strategies were consistent with literature exploring women on the AS's social relationships (Bargiela et al., 2016; Tierney, Burns & Kilbey, 2016) and included effort related fatigue and confusion regarding identity. The current study therefore shed light on the existence

and impact of masking within romantic relationships and the potential for this to negatively impact on young women's self-esteem and identity development.

2.4.2 Identifying vulnerability

Young women in the present study reported being mistreated or exploited within romantic a relationship which aligns with previous findings in the literature related to increased vulnerability (Cridland et al., 2013; Kanfischer, Davies & Collins, 2017). Participants attributed exploitation to factors including a need to avoid conflict and assumptions that the other was "right". This fits with the findings of Bargiela et al. (2016) who found that avoidance of conflict and not knowing how to say no, were factors associated with victimisation for women on the AS. The current study extended these findings as a fear of missing opportunity to form connections, and rejection from partners was reported, which may have contributed to their perceived passivity. Furthermore, all young women described experiencing victimisation during childhood which is thought to be a common experience for young people on the AS (Schroeder, Cappadocia, Bebeko, Pepler & Weiss, 2014). It is difficult to determine whether this contributed to young women in the current study's difficulties within romantic relationships; victimisation in childhood, however, may be a factor which increases risk of future exploitation.

Participants identified a desire to be 'normal' as a vulnerability factor which often led them to engage in behaviours that they did not feel ready for or disliked. The majority of participants did not initially seek the support of others, due to their experiences feeling too painful or frightening. Some reported the use of coping strategies such as "cutting off" as well as substance use to numb difficult

experiences. This may expose young women to potentially risky behaviours.

Endurance of unpleasant sexual sensations was similarly reported by adults on the AS in Penwell Barnett and Maticka-Tyndale's (2015) study and links with anxiety and self-medication have been hypothesised in the AS literature (Arnevikand & Helverschou, 2016).

An important consideration when examining control within participants' relationships is the impact of societal norms and pressures. Feminist theory posits that the unequal social distribution of power between sexes is thought to be due to the creation of structural factors which validate a social order that is dominated by men (Johnson, 1995). This is thought to have encouraged men to exercise control over women including use of violence. Furthermore, those considered to have less power are often vulnerable to being victims of control by those in more powerful positions (Jenkin, 2000). In addition, the social model of disability proposes that individuals are evaluated through a process of power which serves to distance them from mainstream society due to deviating from the norm; such difference is therefore not valued (Owens, 2015). Thus, young women on the AS may be at increased risk of exploitation due to the intersection of multi-faceted layers of disadvantage due to belonging to multiple groups who experience oppression within society. This therefore warrants further exploration in future research in this area.

2.4.3 Constructing the future self

The final superordinate theme to emerge, involved participants' change or maintenance of perceptions which shaped their desires for qualities in partners and the self within future romantic relationships. Participants' experiences can be

understood in terms of the stages of change model which suggests that people make changes in their lives along a continuum of change. However, this is not a linear progression as transition often involves moving back and forth through the stages in a spiral pattern (Prochaska & DiClemente, 1982). Participants' awareness of difficulties and attempts to modify their situation indicated that they had transitioned through stages of contemplation, preparation and for some, action. Recognition of personal limitations was evident in all participants, however, with an emphasis on improving access to education stressed by many. This echoed the findings of Webster and Garvis (2017) who suggested that self-awareness can enable females with autism to overcome barriers and attain desired outcomes when provided with effective support.

Positive growth, however, was apparent in participants' accounts, with many reporting how their experiences had enabled them to detect risk and develop strategies to manage the complexities of romantic relationships in future. As an outcome of their experiences, young women in the current study demonstrated resilience and appeared to develop an ability to exert control over their social environment which was consistent with previous research (Bargiela et al., 2016).

Acceptance was found to be the most desirable quality for a future romantic partner for the majority of participants; however, trust, honesty and companionship were all reported as important factors with physical appearance warranting little significance. This was consistent with values reported by adolescent girls on the AS (Frith, 2004) and those considered NT when considering desirable qualities in friendships (Foggo & Webster, 2017). However, the findings of the present study suggested that participants hoped that a romantic relationship would also lead to personal

development including an increase in confidence and engagement in a process of becoming a “better” version of themselves.

2.4.4 Limitations

The findings of this study should be interpreted within the context of its limitations. Firstly, participants were recruited from a social group for adults on the AS which may have introduced bias due to participants actively seeking support and may therefore have been more inclined to participate due to experiencing difficulties within romantic relationships. If such a selection bias exists, then those who did not experience difficulties in romantic relationships might be underrepresented in our sample. Furthermore, the sample size was small, despite the period of recruitment being extended and methods of engagement being employed (Fayette & Bond, 2017), which may limit the transferability of findings. A potential barrier to participation in qualitative studies has been identified by people on the AS as anxiety concerning face-face interviews due to unpredictability which may have influenced participation (Macleod, Lewis & Robinson, 2014).

2.4.5 Clinical Implications

The findings supported literature which suggests that people on the AS are motivated to establish romantic relationships (Strunz et al., 2016) however, core characteristics of autism coupled with a lack of experience, appropriate support and education may hinder young women from attaining this goal. Trialling innovative methods of intervention which extend beyond the traditional methods of sex and relationship education (SRE) may help to address the needs of young women. Hannah and Stagg (2016) suggested role-play workshops which involve the use of actors to enable individuals to trial approaches and witness potential consequences in a safe

environment. Such directive methods may build upon the use of social skills training groups (Painter, 2006) and Social Stories™ (Gray, 2010) to make the implicit explicit within romantic relationships. Young women, who may have missed opportunities to learn about relationships from peers, may gain an understanding of what to expect within romantic relationships as identified as a need by the current study's participants. Additionally, participants demonstrated personal growth as an outcome of their experiences. The utilisation of such strength should not be underestimated and, within the context of supportive environments, could be built upon to develop the self-efficacy of young women on the AS.

Importantly, the potential for developmental milestones to differ for this group warrants consideration, thus the current timing of SRE may be inappropriate. Providing education at the right time has been recognised as crucial in preparing people with autism for aspects of adult life (NAS, 2018). Educational, health and social settings are implored to increase the frequency and accessibility of this information for people on the AS. Particular attention should be paid to females whose strategies of coping, including masking, may prevent essential needs from being addressed. Education which addresses and normalises individual preferences may also reduce the potential for engagement in activities perceived to be 'normal' by societal standards but which cause distress and discomfort for young women on the AS. This would support recommendations made in Government policy to provide inclusive SRE which reflects diversity and recognises the needs of vulnerable young people (DFE, 2017).

2.4.6 Recommendations for future research

The results of the current study suggest further exploration to improve understanding of how romantic relationships are experienced by women on the AS. There is a paucity of research exploring the lived experiences of this group; women continue to be underrepresented in the literature which may reflect the ratio of men to women who are diagnosed with the condition. There is a clear need to investigate the prevalence and nature of risk factors to abuse as identified by participants in the current study which may be related to qualities associated with autism. Within the current sample, the age at which participants received their diagnosis (mean= 16 Y.O.) reflects the finding that women are more likely to be diagnosed late or not at all (Dworzynski et al, 2012). Women may therefore be at a disadvantage in terms of access to developmentally appropriate support that can come with a diagnosis, including aiding understanding of romantic relationships and how to stay safe.

The current sample consisted of perceivably 'high functioning' participants as all were employed and enrolled in education thus did not appear to have intellectual limitations. It is important, therefore, that future research explores the experiences of women across the full spectrum, including those with more significant communication and intellectual difficulties. The current study indicates that factors associated with autism for females including vulnerability, naivety and masking behaviour, may place those with additional intellectual difficulties at a greater risk of exploitation. Furthermore, all participants in the current study reported experiencing victimisation in childhood. Further research is indicated to explore whether a correlation exists between exposure to victimisation in childhood and experiencing victimisation within relationships in adulthood for women on the AS.

2.5 Conclusion

Young women on the AS may be vulnerable to victimisation and abuse within romantic relationships which echoes the findings of existing literature (Bargiela et al., 2016; Cridland et al., 2013). However, young women in the current study expressed a desire to enter into a trusting, respectful and accepting romantic relationship despite their difficult past experiences. This finding emphasised the importance of the development of support for this group.

The present study highlighted the need to consider the wider context for young women on the AS in light of their experiences of entering into romantic relationships. Increasing awareness of the unique needs of females, the impact of societal influences and the coping strategies they employ to manage differences may enable them to gain the support they need. Further exploration of how autism may increase the risk of victimisation for women is needed to inform the development of educational programmes to enhance safety and reduce the risk of exploitation.

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Chapter 3: Reflective Paper

Reflections on working with young people on the autism spectrum: navigating ambiguity, vulnerability and the future self.

Overall chapter word count (excluding references): 3631

3.1 Introduction

The previous two chapters have explored the qualitative experiences of young people on the AS through both a systematic literature review and an empirical paper. This final chapter is a reflective account of personal experiences of working and conducting research with this population. Reflective practice is a valued concept within the field of clinical psychology and is considered key to continued development within the profession (BPS, 2008).

Throughout the research process, it became apparent that parallels existed between the experiences reported by young women in the empirical paper and those I experienced as a Trainee Clinical Psychologist. These parallels are therefore explored with consideration of the unique challenges I faced when conducting research and working with this group (navigating ambiguity), my own position as a researcher (identifying vulnerability) and personal learning experiences (constructing the future self).

3.2 Navigating ambiguity

3.2.1 Engagement

Despite previous experience of working with young people on the AS, when developing the interview schedule, through consultation of the literature and discussion with my research team, I began to doubt my ability to establish a rapport with participants and thus to enable meaningful information to be adequately captured and shared. I feared that questions would not be explicit enough or that their open-ended nature would inevitably cause participants to feel anxious. It became apparent that there was little known about the best way to facilitate

participation of young people on the AS in qualitative research due to the use of qualitative approaches with this group being in its relative infancy. Research that was available, suggested that some young people on the AS may have trouble answering open-ended questions (Bruck et al., 2007). Additionally, recalling and recounting experiences or events had proved challenging for children on the AS in other research studies (Brown et al., 2012; Milward et al., 2000). Young people were also found to acquiesce when invited to take part in research (Preece & Jordan, 2010). However, following discussion with my research team, it was deemed appropriate to continue to utilise IPA and an open-ended interview schedule due to people with autism being a highly heterogeneous group with a wide range of communicative abilities. Young women were found to generally answer the open-ended questions with ease however, some required additional prompts or clarification and two expressed some difficulty in recalling the details of events. This did not, however, appear to detract from the young women's' rich and detailed accounts. Additionally, participants appeared confident in informing me when they did not understand a question as illustrated in the following extract in which Sam had recalled feeling anxious in a previous relationship:

I: Can you tell me what it is about a relationship that worries you?

P: Meaning?

I: Could you tell me what has made you feel anxious in a romantic relationship?

(Sam, L-207-209).

This experience highlighted the importance of tailoring methodologies to the unique needs of young people on the AS to elicit their views rather than adopting a 'one size

fits all approach' which may restrict the extent of their participation (Harrington, Foster, Rodger & Ashburner, 2014). Consideration of researcher positionality and exploration of possible preconceived beliefs were therefore important factors to consider.

The existence of such beliefs or assumptions was further reflected upon during the recruitment stage of the research process. During the initial stages of recruitment, I contacted gatekeepers from a diverse range of support and social groups for young people on the AS and received varied responses to the request. For example, one gatekeeper suggested that the methodology may not be suitable for young people on the AS as they would struggle to engage with me on a 1:1 basis and also expressed an opinion that members of that group would be unlikely to have had experiences of romantic relationships. This evoked both concern that I may not have adequately considered the needs of the population and frustration at the preconceptions implied by such a response. It led me to reflect on whether this was an assumption often held about people with autism's ability to participate in qualitative research. The existence of such an assumption is represented in the literature (Lewis, 2009) and I wondered whether this may contribute to people with autism being underrepresented in the literature.

My own experience of carrying out the research, however, was that, despite some young people finding elements of the interview challenging, which in part may be explained by the difficult nature of the phenomenon, they demonstrated a determination to talk about their experiences and appeared to really value having an opportunity to share and reflect on them. The majority of participants reported that

they had not discussed their perceptions, experiences or desires for romantic relationships with others before and that their motivation had been to prevent others from having similar detrimental encounters in addition to increasing awareness of needs. This mirrored findings in the literature which suggested that benefits to participants taking part in qualitative research can include catharsis, empowerment and a sense of purpose (Hutchinson, Wilson & Wilson, 1994).

3.2.2 Diversity or disorder?

Conducting research and working as a clinician with young people has enabled me to reflect on societal perceptions of the AS. I became aware of a tension that existed between both my clinical and research roles which was mirrored in the literature including the debate surrounding diagnosis or difference and use of appropriate terminology. Such a dichotomy exists regarding the advantages and disadvantages of diagnostic labels in relation to autism with some research suggesting that the medical model pathologises difference and places emphasis on ‘impairment’ (Baron-Cohen, 2002). The neurodiversity movement (Singer, 1999), however, aims to foster a culture of pride and a community of self-advocacy for people on the AS (Baker, 2011; Jaarsma & Welin, 2012). This debate was especially pertinent to my clinical role, in which formulation is paramount to offering a holistic understanding of an individual’s needs.

Whilst working within a specialist neuro-developmental assessment service, some parents described receiving their child’s diagnosis as “simply words” whilst others questioned whether this would change how they were perceived and treated within society. Young people’s reactions, however, tended to reflect a feeling of relief and

suggested that acquiring a diagnosis, which involved a formulation of their needs, had enabled them to “make sense” of their experiences. Additionally, when conducting my empirical research, young women expressed attempting to ‘fit in’ or to appear ‘normal’ within society, however their perceptions of their diagnosis varied with some accepting autism as part of who they were and others experiencing confusion or resentment in relation to it. In a similar vein, informal discussions regarding diagnosis were had between members of the social group from which participants in my empirical research were a member of. Many spoke of their diagnosis shaping their identity and enabling them to access the support of like-minded individuals. These experiences of how a diagnosis had enabled growth for young people, shaped my understanding of the possible advantages of this approach, including access to appropriate support. This process led me to reflect on where my own values and opinions lay in respect to understanding autism as a diagnosis or difference. I felt able to hold both perspectives in mind, recognising the value of both a psychosocial and a medical model perspective (Kenny et al., 2016). This is in line with research in this area which proposed a ‘deficit-as-difference’ conception of autism which suggests the importance of:

“...harnessing autistic traits in developmentally beneficial ways, transcending a false dichotomy between celebrating differences and ameliorating deficits.” (Kapp, Gillespie-Lynch, Sherman & Hutman, 2012, p. 8).

I encountered a similar debate regarding terminology used to describe the AS. During several research lectures, discussions were had between peers from my cohort and university staff regarding what terminology should be employed by

Clinical Psychologists and whether, within this professional group, we have a duty to reduce stigma for potentially vulnerable populations. Terminology utilised within academic journals, however, was found to be driven by the medical model and therefore decisions regarding appropriate language for our research projects proved challenging. When developing the paperwork for my research I was struck by the wide range of terms used to define autism. Both ‘person-first’ and ‘disability/identity-first’ language was used interchangeably within academic journals, charitable organisation publications and clinical services. I discovered that both forms had been rejected and accepted by the autism community for a variety of reasons and that there was no universally recognised preference. I decided upon the term ‘on the AS’ due to research indicating that this language was consistently favoured across stakeholder groups including people who had autism, their family members and professionals (Kenny, Hattersley, Molins, Buckley, Povey & Pellicano, 2016). However, this diversity and ambiguity further highlighted wider society’s attempt to make sense of the AS, which may reflect the heterogeneous nature of this population.

3.2.3 A girl in a boys’ world?

Throughout the data collection process and during my time working within a specialist diagnostic service, I became particularly aware of the unique difficulties faced by girls and young women on the AS. I had been aware that assessing females could potentially be a challenging process for clinicians. I discovered that girls often presented to the service at a later stage than boys with many found to have mixed observations or reports from settings within the referral and developmental history information. A similar experience was reflected in the interviews conducted with

female participants for my empirical research, as several of the young women were diagnosed in adulthood and reported feeling a range of often conflicting emotions, including confusion and relief. I was particularly interested in the finding that girls appeared to be adept at masking their differences and difficulties coupled with skills in observing and effectively modelling the social behaviours of their peers.

I reflected on my own ability to ‘mask’ aspects of my personality in order to ‘fit in’ within both my professional and personal life, especially as training had required me to change multi-disciplinary teams on a six-monthly basis. I became aware of how masking, as reported by participants, had proved to be both a help and a hindrance and how this strategy could, at times, have limited effectiveness. Following a Peer Led Group (PLG) with my cohort, I recorded in my reflective diary that we had discussed the attitude ‘fake it till you make it’ when reflecting on the challenges of imposter syndrome, a phenomenon well recognised among trainee therapists (Bischoff & Barton, 2002). I recall a similar experience when conducting my first interviews, as I had not undertaken any qualitative methodology since being an undergraduate. The use of methods such as observation and modelling were key to my learning during these experiences and are recommended within the doctoral training programme. I have however, experienced times where I have had difficulty expressing my own needs for fear of appearing inadequate within new teams, often saying ‘yes’ to opportunities regardless of whether I had capacity to complete them effectively.

This illustrated to me that the general population often have difficulty navigating expectations from others, self and society which highlighted the complexity of such

challenges for young people on the AS who have additional social and communication needs. This led me to reflect on societal expectations of women generally and how this may contribute to women on the spectrum's unique challenges. I wondered if it was perhaps less acceptable for women to have such difficulties, to show little interest in social interaction, to have highly specialist interests or to be strongly subjective in their views. For example, Baron-Cohen's (2002) Extreme Male Brain (EMB) theory suggests that males are predisposed to autistic traits due to having greater skills in rule-governed activities and therefore are more likely to be on the AS. Conversely, however, women have been found to possess an innate social drive and ability which may lead to the development of sophisticated masking strategies (Tierney, Burns & Kilbey, 2016). I reflected on the paradoxical nature of these abilities; for young women in my empirical research, victimisation was reported despite demonstrating relatively stronger interpersonal skills. This highlighted the responsibility of clinicians and researchers to continue to gain an understanding of young women on the spectrum whose needs may go unidentified.

3.3 Identifying vulnerability

3.3.1 The researcher 'spectrum'

A dichotomy is thought to exist between researchers who are considered to be either 'insiders' or 'outsiders' with the former defined as those who have *a priori* understanding of a unique culture and its members (Merton, 1972). However, researchers have challenged this assumption, positing that such positioning exists along a continuum (Trowler, 2011). Such 'insider' positionality has been defined as:

“the aspects of an insider researcher’s self or identity which is aligned or shared with participants” (Chavez, 2008, p. 475).

I reflected on my position as a researcher and how my previous experiences had shaped my interest in the field of autism. Prior to embarking on my research, I had supported young people on the AS during my role as a teaching assistant at a secondary SEN school. It was within this role that I developed a passion for working with this group and became aware of the challenges faced by young people regarding navigating the complexities of their social world. Several young people I supported expressed distress related to possessing a strong desire to form connections with peers but lacking the skills to develop these. Additionally, when supporting young people who had a cancer diagnosis in a previous role, those on the AS faced unique challenges when attempting to communicate their needs. These difficulties, for young people in both settings, were often coupled with challenges related to their developmental stage including developing a sense of identity, sexuality and autonomy. A mantra of the charitable organisation that I was employed by was ‘young person first, cancer patient second’ which resonated with my understanding of young people on the AS; these young people faced the same challenges as their peers whilst simultaneously managing differences associated with autism.

Prior to conducting interviews, I also chose to do a neuro-developmental clinical placement as a third-year specialism which involved assessing young people whose differences indicated that they may have autism. I had initially hoped that this would

provide me with an in-depth understanding of the condition as a foundation from which my research would develop from. Upon reflection, I have considered the potential for this to have been a safety behaviour, to reassure participants that I had an understanding and to perhaps reassure myself that I was justified to provide an interpretation of their experiences. I had hoped that this may ‘bridge the gap’ between myself and participants, of which I had initially perceived to be vast.

Despite my prior experience working with young people on the AS, when first visiting the social group from which participants were recruited, I experienced an overwhelming awareness of my ‘outsider’ position. Banks (1998) describes researchers who are perceived to be visiting a community due to interest and a desire to learn as ‘external-outsiders’. Based on guidance in the literature (Fayette & Bond, 2017) and through discussion with the group founder, it was deemed appropriate for me to visit the centre in advance in order for those attending to become familiar with me. .

I noticed that attendees discussed differences and difficulties that they often encountered between themselves and ‘neurotypicals’ (NTs) which heightened my awareness of those difficulties. People on the AS have expressed frustration at the narrow mindedness of NTs and their reluctance to understand difference.

Participants in Hurlbutt and Charmer’s (2002) qualitative study reflected this opinion:

“One of my friends divides NTs into two categories: High Functioning, such as yourself, and Low Functioning, who do not understand us. This is a joke, but it shows my belief in this subject.” (Hurlbutt & Chalmers, 2002, pp.106).

I feared that I would be perceived to be a ‘low functioning’ NT by participants and the wider group. The use of a reflective journal, however, enabled me to explore these processes and how this experience may be akin to what young people on the AS often faced within society. I visited the group between June 2017 and March 2018, during this time I noticed a shift in my status as a researcher from an external to an internal outsider. Banks (1998) described the internal-outsider as a researcher who has been “adopted” or socialised into the community in which they are studying with the potential to reject the values of their own group. I became less concerned with appearing ‘knowledgeable’ when I reflected on the advantages to being an ‘outsider’. Within this position, participants were perceived as ‘experts by experience’. Literature suggests that people on the AS wish to be considered as experts within autism research (Hurlbutt & Chalmers, 2002). Recognising the limits of one’s understanding as a researcher is important in enabling people *with* autism to be consulted on issues *related to* autism; such recognition may serve to empower those participating in research.

3.3.2 Facilitating empowerment

Due to concerns previously discussed, I feared that exposing the young women to a potentially anxiety provoking and distressing experience without the ability to offer interpretation, would serve to contribute to an imbalance of researcher-participant power. Residing in a position of ‘knowing’ in terms of conducting the research,

creating the interview schedule and asking the questions was often an uncomfortable experience. Despite attempts to address this through providing participants with a choice of where and when they wished interviews to take place, an awareness of the contrast with my clinical role existed. As a Trainee Clinical Psychologist, I strive to address this imbalance through efforts to create a collaborative relationship in which clients are active participants in therapy which further highlighted the tension that existed between researcher and clinician roles.

Throughout the research, however, I became aware of how the process unexpectedly appeared to generate moments of empowerment for participants. On several participants asked me questions relating to why I had chosen this topic and why, specifically, had I chosen women. Despite young women being provided with a comprehensive information sheet detailing the rationale, it became apparent that understanding my intentions on a personal level was important to them. I found this an uncomfortable experience initially as I feared that my reply may 'lead' the interview or risk patronising participants. I noted in my reflective diary that this had raised my awareness of what I, as a researcher, expected from participants every time I asked them an, often personal and sensitive, question. In addition, I experienced a similar sense of vulnerability when one young woman asked me if what she was telling me about her experiences was worrying me. It had not occurred to me that participants may be conscious of the potential impact that their experiences may have had on me within the researcher position. I reflected on whether providing a space for participants to engage in a reciprocal interaction had shifted their degree of control. Additionally, the pre-set questions of the interview aided the research process with the content of the interaction being mostly guided by

what was deemed important and relevant to the participant. Young people's narratives were therefore personally rather than researcher driven which may have contributed to a potentially empowering experience.

Whether these interactions had contributed to feelings of empowerment within the research process was not specifically explored with participants. However, the potential for researcher vulnerability to address the power imbalance within qualitative studies has been explored in the literature (Anyan, 2013; Ross, 2017). From reflecting on this process, I recognised the importance of enhancing opportunities for participants to gain a sense of autonomy within research; a theme which mirrored that of the findings from my empirical and literature review regarding support needs of young people on the AS.

3.4 Constructing the future self

My thesis research and clinical placement experiences have enabled me to explore my thoughts and feelings regarding how the AS is understood and experienced both on an individual and societal level. Reflecting on my experiences throughout my research journey highlighted the parallels between the experiences of participants and my own. During data collection and analysis, I was struck by the common values I shared with young women interviewed; acceptance, trust and honesty were reported to be desired in future partners which mirrored my own values for relationships and also experiencing the desire to 'fit in' both professionally and personally. In line with IPA methodology, I reflected on my position as a researcher and I was struck by my perceived shift from external to internal outsider throughout this process and how advantageous remaining in the outsider position could be.

Furthermore, the finding that people on the AS are often not invited to take part in qualitative research might reflect an assumption that such individuals' differences would prevent them from being able to offer useful insight (Whitehurst 2007). This is a viewpoint that I would strongly contest in light of my experiences of conducting qualitative research with this population.

I have inevitably learned from these experiences and they have served to hone my interest and enthusiasm for working with and supporting such a diverse group where consideration of individual difference is paramount. I have learned that despite young people on the AS being a potentially vulnerable group, through my experiences I have witnessed the drive and strengths that young people from this population possess and how effective support can promote their autonomy; building upon and not replacing these qualities. With this new insight, I have developed an appreciation for qualitative research which can have transformative power; providing often disenfranchised people with an opportunity to give voice to their experiences.

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Appendix A

Author instructions for *Research in Autism Spectrum Disorders*

GUIDE FOR AUTHORS

Editorial Process

All submissions will first be checked against the Aims and Scope and Guide for Authors by the Editor-in-Chief. Papers found to conform, in principle, to the journal's remit and standards will be assigned to a handling Editor (an Associate Editor or the Editor-in-Chief) for further evaluation. If a paper meets the journal's criteria a minimum of two independent reviewers will be invited to comment on the paper's methodological rigour and significance. Based on these comments and additional opinions if necessary, the handling Editors will make a decision. All accepted papers will therefore have received comments from a minimum of two independent reviewers and be reviewed by one or more editors. **Please note that RASD currently operates single-blinded peer review.**

Human and Animal Rights

If the work involves the use of animal or human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans <http://www.wma.net/en/30publications/10policies/b3/index.html>; EU Directive 2010/63/EU for animal experiments http://ec.europa.eu/environment/chemicals/lab_animals/legislation_en.htm; Uniform Requirements for manuscripts submitted to Biomedical journals <http://www.icmje.org>. Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed. All animal studies need to ensure they comply with the ARRIVE guidelines. More information can be found at <http://www.nc3rs.org.uk/page.asp?id=1357>

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MANUSCRIPT PREPARATION & SUBMISSION

Use of word processing software

Files must be saved in the native format of the word processor and the text should be in 10-point Arial font, single-column format, double spaced, with standard 1 inch page margins (2.54 cm). Please keep the layout of the text as simple as possible, as most formatting codes will be replaced on processing the article. In particular, do not use the options to justify text or hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. Note that source files of figures and text graphics will be required whether or not you embed them in the text. See also the section on Electronic artwork below for details on preparing figures and graphics.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel they require support in editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop (<http://webshop.elsevier.com/languageediting/>).

In relation to terminology, we prefer authors to refrain from using the terms 'low-functioning' or 'high-functioning' to describe individuals with ASD who either have additional intellectual or language impairments or not (see Kenny et al., 2015; <http://aut.sagepub.com/content/early/2015/06/10/1362361315588200.abstract>). Instead authors should consider whether it may be appropriate to provide details about their participants in terms of the severity specifiers of the DSM-5 (American Psychiatric Association, 2013).

Types of Articles

Research in Autism Spectrum Disorders publishes the following types of manuscripts:

Brief reports: Papers of no more than 2,500 words that report an original piece of research of limited scope and/or that serves as proof-of-principle for larger-scale studies.

Regular Articles: Papers of up to 6,000 words that report a substantive piece of research that makes a significant contribution and has clear implications for practice. Manuscripts reporting the results of randomized trials or interventions must demonstrate adherence to the CONSORT guidelines (<http://www.consort-statement.org/>) and include the relevant flow diagram and completed checklist.

Reviews: Papers of up to 10,000 words that provide a comprehensive overview of a significant area of research. Quantitative (e.g., meta-analyses) and qualitative reviews are welcome as long as they go beyond a mere description of the available literature and synthesise new knowledge with clear implications for future directions and practice. For systematic reviews and meta-analyses, authors must demonstrate adherence to the PRISMA guidelines (www.prisma-statement.org) and include the relevant flow diagram and checklist.

Commentaries: We welcome brief commentaries of no more than 1,000 words that offer new insights on papers published in RASD or elsewhere. Commentaries on government policy and/or items in the media are also welcome.

NOTE: Word limits do not include the title page, abstract, figure legends, tables and reference list.

Submission

Our online submission system guides authors stepwise through the submission process. The system converts article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

Elsevier accepts electronic supplementary material such as supporting applications, high resolution images, background datasets, sound clips and more. These will be published online alongside the electronic version of your article in Elsevier Web products, including ScienceDirect: <http://www.sciencedirect.com>. For further information, please visit our artwork instruction pages at <http://www.elsevier.com/artworkinstructions>

The journal also encourages authors to submit an AudioSlides presentation with their published article. AudioSlides are brief, webinar-style presentations that are shown next to the online article on ScienceDirect, giving authors the opportunity to showcase their work more readily. More information and examples are available at <http://www.elsevier.com/audioslides>. Authors of articles in this journal will automatically receive an invitation e-mail to create an AudioSlides presentation after acceptance of their paper.

To increase the transparency of editorial information within the framework of single/ double blind peer review, RASD displays the number of unique reviewer reports received in the first round of review with each published article. This policy will be in place for original research articles submitted from 1 January 2016 that are accepted for publication.

Manuscript Format

All manuscripts must include a Title, Abstract and Highlights on separate pages, followed by the main manuscript text. The main manuscript text of brief reports, regular articles and quantitative reviews should include subsections carrying the headings Introduction, Methods, Results, Discussion & Implications. Reviews may deviate from this structure but must include a methods section that provides details on how the relevant literature was searched. The structure of commentaries is at the discretion of authors.

Essential Title Page Information

Title: Titles must be concise and informative and should have no more than 20 words. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

Appendix B

Coventry University Ethical Approval-Literature Review



Certificate of Ethical Approval

Applicant:

Jayne Pattinson

Project Title:

Victimisation experiences of children and young people with an Autism Spectrum
Condition (ASC): A review of qualitative research.

This is to certify that the above named applicant has completed the Coventry
University Ethical Approval process and their project has been confirmed and
approved as Low Risk

Date of approval:

16 March 2018

Project Reference Number:

P63839

Appendix C

Author instructions for *Autism and Developmental Impairments*

Only manuscripts of sufficient quality that meet the aims and scope of *Autism & Developmental Language Impairments* will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you



1. Open Access

Autism & Developmental Language Impairments is an open access, peer-reviewed journal. Each article accepted by peer review is made freely available online immediately upon publication, is published under a Creative Commons license and will be hosted online in perpetuity. Publication costs of the journal are covered by the collection of article processing charges which are paid by the funder, institution or author of each manuscript upon acceptance. There is no charge for submitting a paper to the journal.

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2. Article processing charge (APC)

ADLI is an Open Access publication; all articles are freely available online immediately upon publication. All articles are rigorously peer-reviewed, and brought to publication as rapidly as possible. The costs of peer-review and production are covered by Article Processing Charges (APC) paid by the author/institution/funder upon acceptance of the manuscript.

For an extended introductory period all APCs will be waived, a policy that will be reviewed as the journal establishes itself. In future an APC will be set at a level appropriate to the discipline, with a waiver policy available for those authors who do not have the means to cover the APC.

If, after peer review, your manuscript is accepted for publication, a one-time article processing charge (APC) is payable. This APC covers the cost of publication and ensures that your article will be freely available online in perpetuity under a Creative Commons licence.

The article processing charge (APC) is \$3,000 or £1,500.

*If the paying party is based in the European Union, to comply with European law, value added tax (VAT) must be added to the APC. Providing a VAT registration number will allow an institution to be exempt from paying this tax, except for UK institutions.

[Back to top](#)

3. Article types

Research Reports: a full report of a research study using appropriate quantitative or qualitative methods. Maximum length 8000 words. Authors of articles over this length should consult with the editor before submitting.

Reviews: a systematic or systematically-conducted review of theoretical or clinical topics or issues that entails a critique of current research or addresses significant issues or takes a novel and interesting view. Maximum length 10,000 words.

Short Reports: a short paper reporting some preliminary or interesting results from a well-conducted study or a small scale study that is useful but not conclusive. Maximum length 5000 words.

Theoretical Reports: an exposition or critique of particular theory or theories relevant to autism and/or developmental language impairments, with new and original insights. Maximum length 8000 words.

Discussions: a relatively short discussion of theoretically or clinically relevant topics or issues. Commissioned by the editor(s) only. Maximum 4000 words.

3.1 Special Collections

You can submit your paper to one of the following special collections:

- Comorbidity in autism spectrum disorder and developmental language impairments.

See the call for papers [here](#)

- Gesture Development and Use in Individuals with Autism and Developmental Language Impairments. See the call for papers [here](#)

- The Relationship between Motor Development and Language Development in Individuals with Autism and Developmental Language Impairments. See the call for papers [here](#)

Appendix D

Quality Framework (Caldwell et al., 2005) and rating scores for included studies

Quality Framework	Altmore (2017)	Carrington (2017)	Cook, A; Ogden, J & Winstone, N. (2017)	Cook, A; Ogden, J & Winstone, N. (2016)	Fisher & Taylor (2015)	Humphrey & Lewis (2008)
Does the title reflect the content?	Yes	Yes	Yes	Yes	Yes	Yes
Are the authors credible?	Yes	Yes	Yes	Yes	Yes	Yes
Does the abstract summarise the key components?	Yes	Yes	Yes	Yes	Yes	Yes
Is the rationale for undertaking the research clearly outlined?	Yes	Yes	Yes	Yes	Yes	Yes
Is the literature review comprehensive and up to date?	Yes	Yes	Yes	Yes	Yes	Yes
Is the aim of the research clearly outlined?	Yes	Yes	Yes	Yes	Yes	Yes
Are all ethical issues identified and addressed?	Partial (reference to ethical approval)	Partial (reference to ethical approval)	Yes	Yes	No	Yes
Is the methodology identified and justified?	Yes	Partial	Yes	Yes	Yes	Yes
Are the philosophical background and study design identified and the rationale for choice of design evident?	Partial (philosophy)	Partial	Partial (philosophy)	Partial (philosophy)	Partial	Yes
Are the major concepts identified?	Yes	Yes	Yes	Yes	Yes	Yes
Is the context of the study outlined?	Yes	Yes	Yes	Yes	Yes	Yes
Is the selection of participants described and the sampling method identified?	Partial	Yes	Yes	Yes	Yes	Partial (no demographic details)

Is the method of sample collection auditable?	Yes	Partial	Yes	Yes	Yes	Partial
Is the method of data analysis credible and confirmable?	Yes	Partial (lacking information)	Yes	Yes	Yes	Yes
Are the results presented in a way that is appropriate and clear?	Yes	Yes	Yes	Yes	Yes	Yes
Is the discussion comprehensive?	Yes	Yes	Yes	Yes	Yes	Partial (conclusion not distinct)
Are the results transferable?	Partial	Partial	Partial	Partial	Partial	Partial
Is the conclusion comprehensive?	Partial	Yes	Yes	Yes	Yes	Yes
Score	31	30	34	34	32	32

Quality Framework	Humphrey & Symes (2010)	Penny (2013)	Robertson, S. M (2013)	Saggers et al (2017)
Does the title reflect the content?	Yes	Yes	Yes	Yes
Are the authors credible?	Yes	Yes	Yes	Yes
Does the abstract summarise the key components?	Yes	Yes	Yes	Yes
Is the rationale for undertaking the research clearly outlined?	Yes	Yes	Yes	Yes
Is the literature review comprehensive and up to date?	Yes	Yes	Yes	Yes
Is the aim of the research clearly outlined?	Yes	Yes	Yes	Yes
Are all ethical issues identified and addressed?	Yes	Yes	Yes	Yes
Is the methodology identified and justified?	Yes	Yes	Yes	Partial
Are the philosophical background and study design	Partial	Yes	Yes	Partial

identified and the rational for choice of design evident?				
Are the major concepts identified?	Yes	Yes	Yes	Yes
Is the context of the study outlined?	Yes	Yes	Yes	Yes
Is the selection of participants described and the sampling method identified?	Partial (lacking info re. Recruitment)	Yes	Yes	Partial (lacking sampling)
Is the method of sample collection auditable?	Yes	Yes	Yes	Yes
Is the method of data analysis credible and confirmable?	Yes	Yes	Yes	Yes
Are the results presented in a way that is appropriate and clear?	Yes	Yes	Yes	Yes
Is the discussion comprehensive?	Yes	Yes	Yes	Yes
Are the results transferable?	Partial	Partial	Partial	Partial
Is the conclusion comprehensive?	Yes	Yes	Yes	Yes
Score	33	35	35	32

Appendix E

Coventry University Ethical Approval-Empirical Paper



Certificate of Ethical Approval

Applicant:

Jayne Pattinson

Project Title:

An exploration of the experiences of young women entering in to romantic relationships who have an Autistic Spectrum Condition (ASC).

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

03 March 2017



Project Reference Number:

P50391

Appendix F

Gatekeeper consent form

Coventry University
Gatekeeper Consent Form

Title of Project: An exploration of the experiences of young women entering in to romantic relationships who have an Autistic Spectrum Condition (ASC).

Researcher contact details:
Jayne Pattinson- Trainee Clinical Psychologist: Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starley Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: pattinsj@uni.coventry.ac.uk

Please tick to confirm your understanding of the study and that you are happy for your organisation to take part and your facilities to be used to host a space for interviews to take part.

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☒
2. I understand that participation of our organisation and members in the research is voluntary and that they are free to withdraw at any time, without giving a reason. ☒
3. I understand that any personal information collected during the study will be anonymised and remain confidential. ☒
4. I agree for our organisation and members to take part in the above study. ☒

Name of Gatekeeper: *J. Micklewright* Date: *5/7/17* Signature: *JULIA Micklewright*

Name of Researcher: *J. Pattinson* Date: *5/7/17* Signature: *[Signature]*

Name of Person taking consent:
(if different from researcher) Date: Signature:

2

Appendix G

Participant information sheet

will have access to this recording and the document will not include any personal identifiable information to ensure that your identity is protected. Once the voice recordings have been transcribed they will be permanently deleted. Following study completion, your information will be kept securely in a locked room for five years, in line with Coventry University and British Psychological Society (BPS) guidelines.

Study findings, including anonymous quotes and extracts, may be included in the final paper, for the doctoral thesis submission and any further dissemination, such as journal articles and conference presentations. You will be given the opportunity to have a summary of the results of the study upon its completion should you feel that this would be beneficial.

What are the advantages and disadvantages to taking part?

It is anticipated that taking part in the interview may provide a helpful opportunity to share your experiences and to have your views listened to. However, when discussing your experiences, it is possible that sensitive or emotive topics may be touched upon. If you do experience any difficulties, please remember that the interview can be stopped at any time and you can withdraw from the study. Information on local support services will also be available to you.

Who has reviewed the study?

The research study is subject to ethical approval from Coventry University and as such, it will adhere to the codes of ethical practice and conduct outlined by the university.

What happens next?

If you decide that you would like to be contacted about taking part in this research, please complete the consent form attached and return it to Coventry University in the pre-paid envelope provided.

Contact Details

Thank you for taking time to read this information. If you would like further information about the study, you can contact:

Lead Researcher

Jayne Pattinson- Trainee Clinical Psychologist: Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starkey Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: pattinsj@uni.coventry.ac.uk

Academic Supervisors

Dr Jacky Knibbs- Clinical Psychologist: Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starkey Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: j.knibbs@coventry.ac.uk

Dr Tom Patterson- Clinical Psychologist: Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James Starkey Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: aa5654@coventry.ac.uk

Appendix H

Participant consent form



Participant Consent Form

Title of Study: An exploration of the experiences of young women entering in to romantic relationships who have an Autistic Spectrum Condition (ASC)

Principal Researcher: Jayne Pattinson (Trainee Clinical Psychologist)

Please read the information below and place your initials in the right-hand boxes if you agree with the following statements:

1. I have read and understood the information sheet outlining the study. ☐
2. I have had the opportunity to ask questions and I feel satisfied that these were responded to. ☐
3. I understand that if I wish to discuss the research further, or have any additional questions relating to the research, I can contact the research team as detailed on the information sheet. ☐
4. I understand that my participation in this study is voluntary and that I can withdraw at any time. I also have the right to withdraw my data from the study up until two weeks following the interview. I will not need to provide a reason for this and this will not affect any support services that I am involved with in any way. ☐
5. I am aware and consent to the interview being digitally recorded. Any personal or identifiable information will be removed from the transcription of the interview. ☐
6. I confirm that I agree to take part in the research study outlined in the information sheet. ☐

Name of participant

Signature

Date

Name of researcher

Signature

Date

Appendix I

Interview schedule



Interview Schedule

An exploration of the experiences of young women entering in to romantic relationships who have an Autistic Spectrum Condition (ASC).

Prior to the interview taking place, the lead researcher will discuss with the participant the use of the term Autistic Spectrum Condition (ASC) and determine whether they identify with this term or if they would rather use a preferred term.

1. I wondered if you could tell me a little bit about yourself and your family?

Prompt- Life experiences, home life, relationships with others

2. Could you tell me about your social life?

Prompt- Current, work, school

3. Can you tell me about any experiences of entering in to a relationship that you have had?

Prompt- How did you feel about these experiences? Are there things you would now do that are like or different from these experiences?

4. Can you tell me about what a relationship/intimacy would mean to you?

Prompt- How would this impact on your life?

5. What are your hopes for a relationship?

Prompt- What would you like to gain from being in a relationship?

6. Can you tell me about any concerns that you might have about entering into a romantic relationship?

Prompt- Is there anything that worries you? How do these concerns have an impact?

7. Are you able to describe any difficulties that you have had personally with relationships?



Prompt- What happened? What did you find most difficult? How have you made sense of those difficulties?

Additional questions if appropriate:

8. Could you tell me about how you feel you are similar or different to your peers?

Prompt- How do you feel this has impacted on your life?

9. Can you tell me how you feel about Autism (chosen preferred term)?

Prompt-What do you think about ASC? How does Autism relate to you?

10. How do you feel your life would differ if you were to be in a relationship?

Prompt- What would your life look like? How would your life change? How would you see yourself?

11. Could you tell me how you see your future?

Prompt-What would you like to do? What would be important for you to experience/achieve?

Appendix J

Demographic information form



Demographic Information

An exploration of the experiences of young women entering in to romantic relationships
who have an Autistic Spectrum Condition (ASC).

Please provide the research team with some additional information about you by answering the following questions. All responses will be kept confidential and will be used solely for the purposes of the research study.

Full name	
Date of Birth (D.O.B)	
Age (In years)	

How would you describe your ethnicity? (Please indicate by ticking the relevant box)

White	British	
	Irish	
	Other	
Mixed	White and Black Caribbean	
	White and Black African	
	White and Asian	
	Other mixed	
Asian/Asian British	Indian	
	Pakistani	
	Bangladeshi	
	Other Asian	
Black/Black British	Caribbean	
	African	
	Other Black	

How old were you when you were given a diagnosis of an Autism Spectrum Condition?

.....



What is your current relationship status? (Please indicate by ticking the relevant box)

Single	
Married/Civil partnership	
Living with partner	
In a relationship but not living with partner	
Divorced	
Widowed	
Prefer not to say	
Other (please specify)	

This question is about your employment status. Do you identify as: (Please indicate by ticking the relevant [box](#))

Full time employed	
Part time employed	
Self employed	
Unemployed	
Student	
Unable to work	
Other (Please specify)	

This question is about your sexual orientation. Do you identify as: (Please indicate by ticking the relevant [box](#))

Gay/lesbian	
Heterosexual/straight	
Don't know	
Prefer not to say	
Other (please specify)	

Thank you for taking time to complete this questionnaire.

Jayne Pattinson (Trainee Clinical Psychologist)

Lead Researcher

Coventry and Warwick Universities

Appendix K

Debriefing form



Debriefing Form

An exploration of the experiences of young women entering in to romantic relationships
who have an Autistic Spectrum Condition (ASC)

Summary of Research and Aims

Thank you for taking part in this research and for agreeing to be interviewed. The interview was designed to better understand your lived experiences of entering romantic relationships.

A summary of the research findings will be made available to you upon its completion, please indicate your interest in receiving this summary on the form below. Should you wish to withdraw from this study, you are reminded that you can do this up until 2 weeks following the interview.

While discussing your experiences, it is possible that we may have talked about sensitive or emotive topics. If you feel that you would benefit from further support related to this, please refer to the following services that may be of support to you:

Autism West Midlands is an organisation aimed at supporting individuals who have a diagnosis or identify as being on the Autistic Spectrum. You can access advice and support via the following contacts:

Website: <http://www.autismwestmidlands.org.uk/contactus>

Telephone: Reception: 0121 450 7582/ Helpline: 0303 03 00 111

Email: info@autismwestmidlands.org.uk

Your GP will also be able to provide you with information regarding talking therapies and counselling should you feel that this may be of benefit to you.



Contact Details:

Lead Researcher

Jayne Pattinson- Trainee Clinical Psychologist: Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James ~~Stanley~~ Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: pattinsj@uni.coventry.ac.uk

Academic Supervisors

Dr Jacky ~~Knibbs~~ Clinical Psychologist: Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James ~~Stanley~~ Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: j.knibbs@coventry.ac.uk

Dr Tom Patterson- Clinical Psychologist: Clinical Psychology Doctorate, Faculty of Health and Life Sciences, Coventry University, James ~~Stanley~~ Building, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328 Email: aa5654@coventry.ac.uk

Thank you for taking part in this study, your time is greatly appreciated.

Jayne Pattinson

Trainee Clinical Psychologist

Universities of Coventry and Warwick.

Are you interested in receiving a summary of the study's results (Please tick)?

Yes ☐
No ☐

If you have answered yes, please provide contact details as to where you would like the results summary to be sent:

Appendix L

Stages of data analysis (Smith et al., 2009, pp.82-101)

	Step	Process
1.	Reading and re-reading	<ul style="list-style-type: none">• Immersing oneself in the data: ‘entering the participant’s world’
2.	Initial noting	<ul style="list-style-type: none">• Examination of the semantic content and language use at an exploratory level.• Descriptive, linguistic and conceptual comments are made.
3.	Developing emergent themes	<ul style="list-style-type: none">• Managing the data changes as attempts are made to reduce the volume of detail.• Themes reflect the participant’s words and but also the analyst’s interpretation.
4.	Searching for connections across emergent themes	<ul style="list-style-type: none">• Development of a mapping of how the analyst thinks the themes fit together.• Patterns and connections identified to develop superordinate themes.
5.	Moving to the next case	<ul style="list-style-type: none">• Treating the next case as its own, through bracketing, is important whilst repeating the previous processes.
6.	Looking for patterns across cases	<ul style="list-style-type: none">• Reconfiguration of themes as patterns emerge across cases.

Appendix M

Excerpt from data analysis

Excerpt from Jo's transcript demonstrating the process of descriptive (green), linguistic (pink) and conceptual (yellow) coding:

I: How did you deal with that when you felt that way?

P: I just kind of had to cut him off which wasn't fantastic because he was also a good friend beforehand but erm (pause) I didn't know how else to deal with it. I just found the feeling very **confusing and scary**. — **intensity of fear**.

I: Had you had any feelings like that before? — **unclear**

P: (Pause) I think I have but I've never really acted on it before because I just didn't understand them. — **suppression?**

I: So that was the first time you'd felt that there was potential for a relationship with this person

P: Yeah it was

I: Can you tell me a little bit more about the sorts of feelings that you noticed?

P: I can try (laughs) It's quite difficult but erm (pause) I would say **happy and stuff but also very anxious and insecure and uncertain** and I **actually felt very scared**. I'm not sure if it was even in a bad way but I felt scared (laughs). — **is there a point he scared?**

I: So how did you know that he wanted to enter in to a relationship with you?

P: (Pause) One because he told me and erm (pause) two because of just the way he acted like say he would put his head **on my shoulder, this and the other or say touch my hand and all that sort of stuff**. Just the way he acted as well.

I: How long did he his behaviour continue like that for before he told you?

P: Probably about four months. Three or four months.

I: What was that period like for you?

P: I kind of knew, because it's not the first time it's happened.

I: With the same person?

P: No different people but no, it's not the first time it's happened. kind of new but it was a bit difficult because I was **confused** more than anything. Yeah definitely **confused** about it (laughs) because I didn't know what, sort of, what was happening.

I: Can you tell me about what was causing you to feel scared?

P: When I got the feelings I got quite scared because I didn't know what they were but also when he became obsessive yeah I felt quite scared because I wasn't intimidated as such but I just didn't know what was going on really. Well I kind of did kind of didn't but I just didn't understand it. None of this worries you does it?

I: No

P: I was going to say, yeah (laughs), good.

I: Can you tell me about what happened when you cut him off? What happened then?

Annotations:

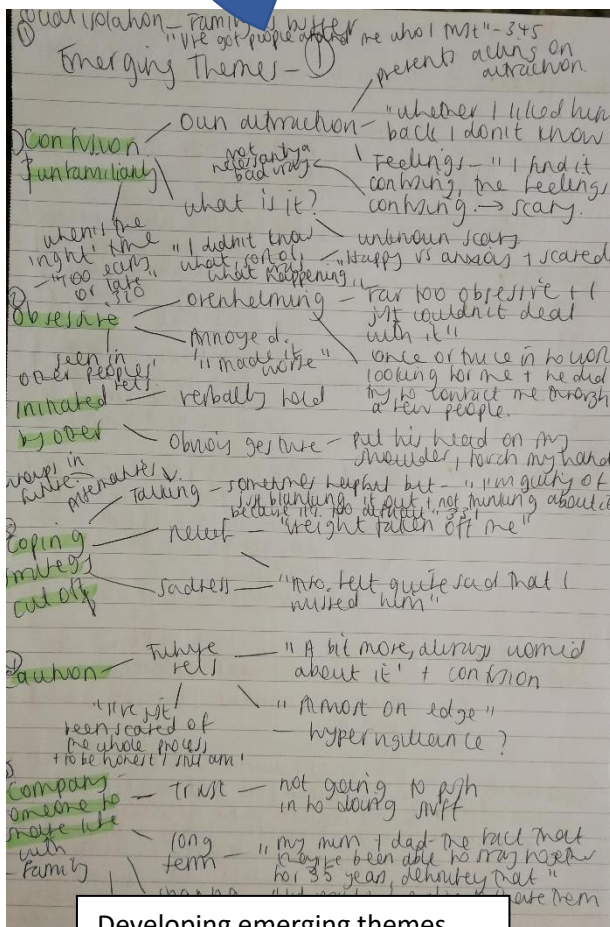
- Coping strategy?**
- black + white**
- lack of automaticity**
- Indifference**
- minimisation of experience**
- loss of particularly importance her x1 on the spectrum**
- anxiety related to one unknown**
- experience of new emotion (what is it?)**
- Fear response overwhelmed the positive**
- minimisation of experience - shame? - how will this be interpreted?**
- clear, obvious signals - verbal or physical gesture - no mention of vibration.**
- Repetition of confusion.**
- loss of control - unable to predict consequences**
- incoherence of comment at first - fear of abnormality, prediction of action of researcher.**
- intensity**
- unknown**

Appendix N

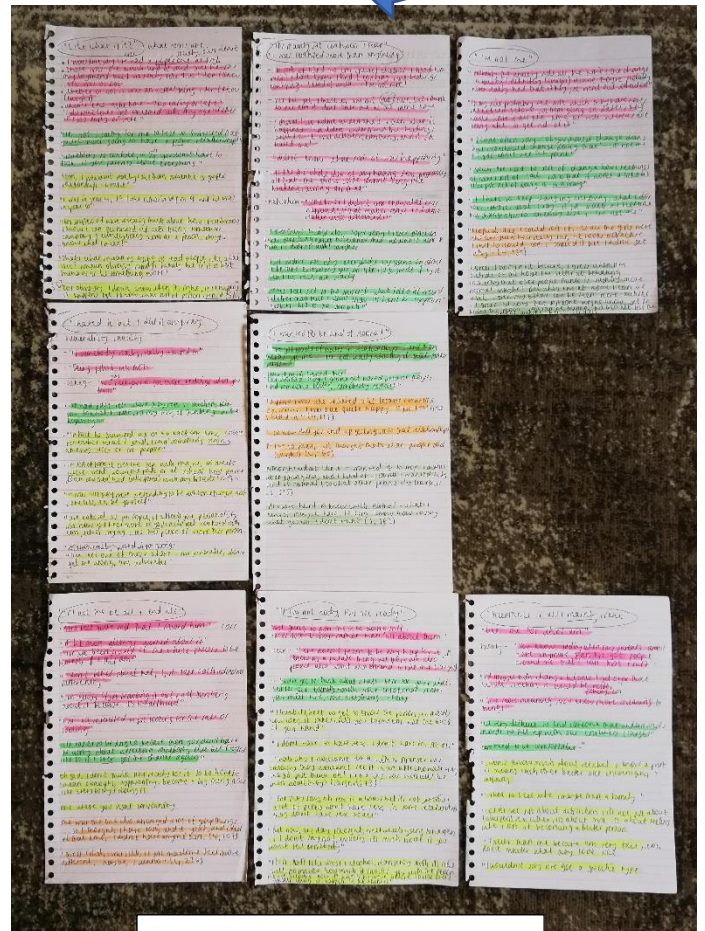
The process of theme development across transcripts.



Identification of patterns across themes.



Developing emerging themes from individual transcripts (E.g. Jo).



Identification of recurrent themes.